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Design Strategy for Integrated Personal Health Records: Improving the User Experience of Digital Healthcare and Wellbeing

Dissertação para obtenção do Grau de Doutor
em Media Digitais

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Design Strategy for Integrated Personal Health Records: Improving the user experience of digital healthcare and wellbeing

Dedication

to my great grandmother,
a Spanish woman who built our future with her stamina,

to my grandmother,
a strength of nature at the age of 97 years old,

to my mother, an artist, a teacher and devoted caregiver,
who has warmed our hearts with her paintings,

to my father, a problem-solving mind, engineer and photographer,
and his craving for humans to reach their full potential,

to all my family.

PhD Program

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UT Austin | Portugal

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I remember the day I left my last job as a UX designer, to pursue this PhD. When I left the headquarters of Nokia Siemens Networks, the sky was alive with a beautiful sunset. At that time, I already had in mind what would be the quest of my thesis. By chance, on the way to my car, I came across an elderly man who was lost on the freeway and fell down, next to me. Naturally, I guided this man to the company's doorman who explained that this person suffered from Alzheimer's and it wasn't the first time he was lost on that freeway. I remember the feeling I had. I was sure, I was making the right decision and perhaps the work I was about to begin, could provide its contribution for improving the quality of care, by empowering people to self-manage their health and wellbeing, avoiding this type of events.

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Abstract

This dissertation addresses the timely problem of designing Integrated Personal Health Records (PHR). The goal is to provide citizens with digital user experiences, sustainable and flexible enough, for gaining control over their personal health information in a seamless way. Most importantly, so that people are able to reflect and act upon their self-knowledge, towards the accomplishment of their good health and wellbeing. Towards this end, the Integrated PHR as an emerging model in the field of Health IT, was the framework that set this research forward on exploring how communication and collaboration between patients and providers can be improved, which naturally impacts the field of HCI.

Acknowledging that today patients are the ones who own all that is recorded about their health data, this new model was object of a design strategy that shaped the results presented in this dissertation. These have showed how patients can have more control of their health over time, through a patient-centered, organic system, which has the ability of combining multiple sources of data both from patient and provider side. As this new type of PHR fosters the creation of integrated networks, this milestone was achieved in this research by interacting with cross-channel user experiences that took part of nationwide healthcare ecosystems.

The work presented herein, has demonstrated through the analysis and development of two use cases in cooperation with organizations connected to the Portuguese Ministry of Health, how an Integrated PHR can be a powerful personal tool, to be used by the citizen with undeniable value to the demands of an aging society. The use cases structured the thesis into two parts. The first part in collaboration with the Portuguese National Patient Portal, combines an Integrated PHR and incorporates the Portuguese Data Sharing Platform (PDS), which can be used by any Portuguese citizen. This use case study led to a

proposal of the portal by also creating a foundational model for designing Integrated PHRs. The second part in collaboration with the Portuguese National Senior Telehealth Program (Saúde 24 Sénior), led to another proposal for an Integrated PHR, applying the outcomes from Part 1 and the requirements that derived from the findings explored in this second use case study. The proposed solution, has the potential to be used by the Portuguese senior community in the scope of home assistive care.

Both proposals applied a user experience design methodology and included the development of two prototypes. The engagement of the stakeholders during the two case studies was accomplished with participatory design methods and followed a multidisciplinary approach to create solutions that would meet the human, politics and behavior interdependencies that were inherent to the process of working with large healthcare organizations.

The provided contributions from this thesis intent to be part of a transition process that is changing the behavior of the healthcare sector, which is increasingly moving towards the improvement of the patient-provider relationship, patient engagement, collaborative care and positive computing, where digital technologies play a key role.

Resumo

Esta dissertação aborda o problema oportuno da criação de Processos de Saúde Pessoais Integrados (PHR integrado). O objetivo é proporcionar aos cidadãos experiências de utilização digitais, suficientemente sustentáveis e flexíveis, para que estes possam obter um maior controlo sobre as suas informações de saúde pessoais de uma forma simples e natural. Mais importante ainda, para que as pessoas possam refletir e agir sobre o seu autoconhecimento, na busca de alcançarem uma boa saúde e bem-estar. Para este fim, o PHR integrado como modelo emergente no campo dos sistemas de informação de saúde, foi a estrutura que impulsionou esta investigação na exploração sobre como a atual comunicação e a colaboração entre os pacientes e os prestadores de cuidados pode ser melhorada, o que naturalmente tem impacto no campo da Interação Pessoa Máquina.

Tendo consciência e assumindo que hoje os pacientes são os detentores de toda a informação de saúde que é registada sobre si, este novo modelo foi objeto de uma estratégia de design que moldou os resultados apresentados nesta dissertação. Estes demonstraram como os pacientes podem ter um maior controlo sobre a sua saúde ao longo do tempo através de um sistema orgânico centrado no paciente, que tem a capacidade de combinar múltiplas fontes de dados que têm origem tanto do lado do paciente como dos prestadores de cuidados. Como este novo tipo de modelo promove a criação de redes integradas, este marco foi alcançado nesta investigação através da interação com experiências transversais multi-canal que tiveram lugar em ecossistemas de saúde de âmbito Nacional.

O trabalho aqui apresentado demonstrou, através de uma análise e desenvolvimento de dois casos de estudo em cooperação com organizações interligadas com o Ministério da Saúde em Portugal, como um PHR integrado pode ser uma poderosa ferramenta pessoal para ser utilizada pelo cidadão, inestimável para as exigências que advêm de uma sociedade envelhecida. Os respectivos casos de estudo estruturaram a tese em duas partes.

A primeira parte, em colaboração com o Portal Nacional do Utente que contém um PHR integrado, faz parte da Plataforma Portuguesa de Dados de Saúde (PDS) e pode ser utilizado por qualquer cidadão Português. Este caso de estudo deu origem a uma proposta para o portal, acabando por constituir também um modelo fundacional para a criação de PHR integrados. A segunda parte, em colaboração com o Programa Nacional Sénior de Telesaúde em Portugal (Saúde 24 Sénior), deu origem a uma proposta para o desenvolvimento de outro PHR Integrado, aplicando os resultados da Parte 1 e os requisitos que derivaram dos resultados explorados neste segundo caso de estudo, com o potencial de ser utilizado pela comunidade sénior portuguesa no âmbito da teleassistência em casa.

Ambas as propostas aplicaram uma metodologia de *user experience design*, e contemplaram o desenvolvimento de dois protótipos. O envolvimento dos *stakeholders* durante os dois casos de estudo foi promovido através de diversos métodos de design participativo, seguindo uma abordagem multidisciplinar de forma a criar soluções que respondessem às interdependências humanas, políticas e comportamentais, inerentes ao processo colaborativo com organizações de saúde, de grande dimensão.

As contribuições que resultaram desta tese, pretendem fazer parte de um processo de transição que visa alterar o comportamento do sector da saúde, que procura cada vez mais, melhorar a relação entre o paciente e o médico, promover a participação do paciente na sua saúde, a prestação de cuidados colaborativos, aplicando o conceito de *positive computing,* onde as tecnologias digitais desempenham um papel fundamental.

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Abbreviations

AAL	Ambient Assisted Living
CN#	Communicator Nurse (participant number)
EHR	Electronic Health Record
EPR	Electronic Patient Portal
EMR	Electronic Medical Record
eHealth	Electronic Health
GP	General Practitioner
GHA	Global Health Assessment
HCI	Human Computer Interaction
Health IT	Health Information Technology
IA	Information Architecture
ICP	Individual Care Plan
LCS	Linha de Cuidados de Saúde
MAB	Method for Assessing the Bio-Psycho-Social
NHS	National Healthcare System
ODL	Observations of Daily Living
PHR	Personal Health Record
PDS	Portuguese Data Sharing Platform
PCEHR	Personally Controlled Electronic Health Record
P#	Physician (participant number)

SPMS	Serviços Partilhados do Ministério da Saúde
SDT	Self Determination theory
S#	Senior (participant number)
UX	User Experience
UI	User Interface
UEQ	User Experience Questionnaire

Introduction

'Tree of life' by Helena Caldeira

When we value individual and community knowledge and autonomy, the leaves are golden.

Alan Dix, in British HCI'16

User experience is a well known recognized paradigm in the design and evaluation of artifacts in the human computer interaction field. Its methods have been used in design science to gain a more comprehensive understanding of the user, providing them valuable experiences [200]. Several user experience studies reported in literature, seek to complement the functional analysis and user interaction of systems, with other emotional, social and cultural aspects of relationships that people have with technology [2]. Nevertheless, it has been a challenge for health communication within the domain of information technology to meet these criteria, as there is a lack of involving the beneficiaries of a product, system or service in the design process, resulting on a gap in what concerns meeting the needs of the users [128]. The research presented in this dissertation, is concerned with the enhancement of health communication in peoples lives and also on filling this gap. The main goal of health communication is to empower people with evidence-based information about living a healthy life [128]. As a keynote in HCI 2016, Alan Dix presented in his talk, ways for designers to leverage the power of the large to bring benefits to the small, privileging the information stored at the edges as primary, rather than central repositories. While presenting "The Leaves are Golden - putting the periphery at the center of information design"[1], Alan Dix established a metaphor regarding the design of traditional information systems which often focuses on centralization, privileging global consistency over local knowledge, as following: "the golden copy is at the center, data at leaves are views of this." This metaphor stands along with the goal of this thesis, which is to put the citizen and their own data at the heart of the healthcare information system.

1.1. Background

Ageing is one of the greatest challenges of the 21st century society. We are witnessing an increased demand of delivery of care, due to an important demographic shift of the population growth. Globally, population aged 60 or over is growing faster than all younger groups. Compared to 2017, the number of persons aged 60 or above is expected to more than double by 2050 and the number of persons aged 80 or over is projected to triple [216]. In addition, by 2020 there will be a considerable decline in the number of the nursing staff and in the specialized geriatric workforce [144], thus demanding for new measures to ensure that this fast growing group receives proper care [196]. Fostering good health is a determinant factor to enhance the senior's independency and functionality, helping them to age in place [215] [214]. Undoubtedly, this asks assistive technology and customized solutions to support older people. That is the prompt of several programs around the world such as the European Innovation Partnership on Active and Healthy Ageing. Also, tailored technologies for seniors have proven to positively impact on quality of life, by reducing costs, readmissions and the length of hospital inpatient episodes [87].

1 http://alandix.com/academic/talks/HCI2016-the-leaves-are-golden/

Within this scope, given these increasing demands for improved care, Health Information Technology (Health IT) or Electronic Health (eHealth) that supports health-related human activities, is seen as a key enabler to achieve such a demand for improved efficiency and quality of care [55]. Health IT collects, stores, and displays patient health data that can improve accuracy and collaboration in service delivery resulting in better care [115]. We are facing a transition period that is changing the way healthcare system practices behave today and consequently, affecting peoples' lives: Health IT is moving towards a strategy of transparency and continuity of care with the Electronic Patient Record (EPR) at the core. The time has come where medical records are now digital and incorporated into Electronic Health Records (EHRs), which are hold by healthcare facilities, becoming part of a fast, increasing, pervasive world. In its turn, EHRs can significantly enhance teamwork among clinical professionals by improving information transfer, workflow and communication that consequently affects positively patient safety. Meadows and Chaiken [119] explain how patient care can take clear advantages of clinical information technology solutions. Accordingly, they assert that for high-quality and safe patient care, multidisciplinary teams of professionals are required to work synergistically, remain focused and have appropriate communication channels for sharing patient information among them. Gaps in effective communication may result on professionals to work at cross-diagnosis and treatments, which can lead to suboptimal care and compromised patient safety. Therefore, Health IT or eHealth plays an important role in clinical teamwork. A given example by the authors shows that with the use of a clinical documentation system, such as the EHR, clinicians can complete charting in real time at the point of care in a way that complements their workflow. Information automatically posts to the multidisciplinary record of care so it is instantly available to all care team members. In addition, key patient data are available for clinical decision support during the ordering process. Given the scenario, physicians, nurses and others can now focus on activities that truly affect patient care rather than those that are associated with clinical or administrative rework.

Following this trend, patient information can now be shared across different types of health institutions, connecting healthcare providers and patients. Recently, nation-wide healthcare networks have emerged in several countries around the world, offering cross-channel experiences that connect providers from several facilities with patients, through centralized platforms. Europe is facing a broad change of the healthcare sector that is now being improved by a digital cross-border information exchange strategy for sustainability. Nevertheless, unlike other sectors, very little is regulated at European level in terms of harmonizing health systems and services [52]. Sustainable system innovations or transitions towards sustainability require combinations of technological, cultural, social, institutional and organizational changes that are only possible with stakeholders co-operation [154]. In this context, several government reforms are conducting technological implementation guidelines, with the main goal to empower patients in the control of their health data and engage them in communication with their providers. However, an early study conducted by Symon et al. (1996) [188], for example, points towards issues on politics and conflicts frequently associated with large-scale implementations. The causes for the problems are varied as healthcare work is highly institutionalized and complex, involves multiple stakeholders, takes place across primary, secondary and tertiary care sectors and depended on a highly collaborative approach [55]. A very common concern is regarding the poorly integration of the several systems that support different practices, departments and institutions, which makes coordination a very difficult task. Other studies [175] [55] also suggest that the challenges of implementing new technology in healthcare settings are very complex, diverse and locally situated which inevitably affects the design process for these novel solutions. It depends on organizational, clinical but also human/politics/behavior interdependencies that are the key challenges for design and implementation in clinical practice.

Accordingly, both the European Union's Data Protection Acts and HIPAA - Health Insurance Portability and Accountability Act, in the United States, state that patient's data are owned by the patient and not by the institutions [5]. This is a very important change in mindset: giving the citizens the ownership of their data enables an easier and more ethical way of sharing health data with others. In fact, if citizens own their data, they become case managers of their own medical record and may better decide upon their treatments. Acknowledging this ownership, leads to an enhancement of the person's self-care awareness and decision-making, by providing the person, the access to her clinical history. Moreover, who would be more interested to manage oneself data? The holder of the data or the providers who are responsible for doing their care work, but have many other patients to manage in their busy daily clinical practice?

Personal Health Records (PHRs) are supporting citizens in this new role, through web-based applications. PHRs have the ability to empower the patient, change and improve patient-provider relationships, enhance shared decision making and enable a more personalized patient centered care, helping also to decrease healthcare costs [9] [12] [71]. While EHRs are populated with providers inputs that allow the patient's medical record to be shared across an institution (reporting clinical episodes, diagnosis, care plans and treatments), PHRs are particularly centered on patient self-collected data. PHRs belong to the group of personal informatics systems and wellness devices. They are flexible solutions to access the patient's data anytime, anywhere, providing patient context awareness, monitoring and response to emergency or critical situations [3]. The main advantage however, is to allow users to obtain self-knowledge by collecting information about oneself like one's behavior or habits and be able to reflect on them. Li et al. [103] created a stage-based model of personal informatics systems composed of five stages that can be applied in the design of a PHR: preparation, collection, integration, reflection and action. Preparation stage concerns itself with people's motivation to collect personal information, how they determine what information they will record, and how they will record it. Collection stage is the time when people collect information about themselves. Integration is the stage that lies between the Collection and Reflection stages, where the information collected is prepared, combined, and transformed for the user to reflect on. The Reflection stage is when the user reflects on their personal information. This stage may involve looking at lists of collected personal information or exploring or interacting with information visualizations. Last, the Action stage is when people choose what they are going to do with their newfound understanding of themselves. Some people reflect on the information to track their progress towards goals.

Finally, the evolution of Personal Health Records in Health IT, shows opportunities and challenges for bridging clinical and non-clinical health practices in the field of HCI. There has been a growing interest in the HCI community to study Health, with particular focus in understanding healthcare practices and designing technologies to support and to enhance these practices [29].

1.2. The Integrated Personal Health Record

A new model has emerged to allow patient's data to have a bidirectional flow between PHR and EHR systems designated by Integrated Personal Health Record. The goal of this type of PHR is to enable easy communication between patients and providers and to promote an active, ongoing collaboration, in care delivery and decision making [43]. The novelty of this model is to have a system that gathers patient information recorded from the provider side, and its multiple health-related sources, and the patient side, which can be accessed by both parties but to be managed by the patient who is responsible for its sharing. The provider side includes the several stakeholders that the patient interacts with: nurses, physicians and therapists, among the others who take part of any healthcare environment. In order to be populated with provider's data such as the patient medical record, the system needs to be flexible enough, to connect with other medical systems e.g., being tethered to an EHR from an independent facility or being tethered to a broader healthcare network like a National Patient Portal. Likewise, a single Integrated PHR can detail all the related interactions that occur between patient and providers, and lead to better treatment and seamless healthcare by always being online and up to date. Also, the model helps to increase organizational control and strict auditing (what information was recorded, when and by whom), controlled by the patient.

The design of a system of this kind goes beyond a matter of simply computerizing existing records. Once again, it raises complex conceptual and empirical issues that need to be understood: viewing clinical management decisions as collaborative dependencies on teamwork, has potentially a number of implications for the Integrated PHR [66]. One way to design this new model is to apply an organic approach on Health IT. The early PHR model is closer to the foundations of "mechanistic" Health IT, i.e., focuses on standardized and easy-to measure data such as blood pressure, cholesterol, or menstrual cycle. Instead, organic Health IT can support measures of health status and progress that are more complex to interpret. Marcu et al. [115] have introduced the concept of "organic Health IT" and shared its benefits, which can be applied in the design of Integrated PHRs. According to the authors, the role of organic Health IT could be to provide dynamic visualisation that allow both patient and their clinical team members to explore and annotate the data in order to interpret it collaboratively. This way Integrated PHRs have the potential to go beyond the response to emergency and critical situation, when an unpredictable incident must be handled. Instead, they increase self and team awareness and coordination. The novelty of this model is then, to encourage collaborative reflection by increasing access to information and allowing for multiple perspectives on data and decisions. Therefore, it should account for different types of stakeholder contacts, communication channels, and information needs across a network of providers (some of which need to be more standardized and streamlined, and some of which need to be more informal and flexible). Finally, the design of Integrated PHR should enable the creation and review of records that may need to change over time to account for new or adaptive measures for monitoring chronic conditions.

Another two concepts relevant to the design and development of this model also emerge in this context: (1) The contribution of the system to a new paradigm in the healthcare industry introduced by the movement of “participatory medicine”. The paradigm motivates patients and providers to work together as a team, focusing on the person’s health improvement [5]. (2) The system as an engine of human behavior change, allowing health outcomes to be measured and collected through self-tracking tools, either automated (sensor-based) or manual (user inputs). This behavior is defined as “Human measurement-based medicine” that helps providers to make care choices while simultaneously, engages people to make life choices and achieve wellness goals [67]. This can be accomplished with the wide prevalence of smartphone self-tracking applications that are available today (e.g., MyFitnessPal, WeightWatchers) and wearable sensing devices (e.g., Fitbit, Apple Watch, Microsoft Band). Chung et al. [26] have presented how providers recognize the value and benefit of self-tracking data to help achieve five major goals: (1) Supporting diagnosis, (2) Personalizing treatment, (3) Increasing motivation and accountability - help patients to overcome motivational barriers and be accountable for their health issues, (4) Learning about patients and (5) Facilitating discussion and managing visits.

The design and adoption of Integrated PHRs to answer the needs presented so far, is the main motivation that structures this dissertation. Towards a perspective of patient centered care, the research work describes a design strategy that was followed for designing Integrated PHRs. The goal was to create a design model that could engage the citizens to participate in their own health, allowing them to work together with their providers across institutions, towards the accomplishment of their wellness.

1.3. Seniors as a potential group for adopting Integrated PHRs

Besides the most common barriers of privacy and security concerns both from patients and providers, an open challenge is on designing Integrated PHR systems to suit the needs of a wide variety of potential users [104]. As such, studying the context of the users and its condition-specific requirements is highly necessary to engage patients and providers in this new model. As suggested in prior work, a potential user group to adopt Integrated PHRs, are senior people [211] [9] [89]. This is mainly because this group often experiences several care problems at the same time, as a result of the human ageing process (e.g., chronic diseases, visual impairment, hearing loss and dementia). Indeed, this is one of the main reasons for this group to broadly benefit from an integrated digital tool that can help people to manage their problems and prevent critical events.

Additionally, this group is the most affected by the fragmentation and incompleteness of medical records, which in many cases is still a reality, despite the advances of EHRs [9]. Senior people as well as people with long-term conditions, are considered to be the most vulnerable to the inevitable decentralization of health information caused by non-interoperable systems of facilities [174]. Likewise, as they often need to go through several care transitions, moving between facilities or providers during their care treatments, the management of all their data can be quite a challenge. Uncoordinated transitions that happen most of the times, can imperil patients because of omitted, duplicative or contradictory care plans [174] [181]. For instances, communication problems with handoffs in hospitals, where patient information is exchanged between healthcare providers (e.g. during a hospital department transfer), may cause adverse events that can lead to medical errors instead of assuring the continuity of care [70]. Besides these care transitions, the fact that senior people suffer from memory loss, makes them vulnerable to forget important clinical information and past episodes. Accordingly, 40 to 80 % of the medical information provided by the clinicians during a visit is forgotten immediately and almost half the information that patients remember is incorrect [5].

For the reasons mentioned above, it is critical that senior people and their family to become central holders of their patient data and be responsible for its sharing between the several facilities and care transitions episodes they go through, which can be accomplished with the use of an Integrated PHR. Conversely, health status seems to be a strong moderating factor that affects the adoption of technology by senior people. People may be less inclined to use information technology, including applications to improve their quality of life, when they have multiple health problems to deal with, due to lower perceived behavioral control caused by physical or cognitive weakness [69]. For that reason, technology needs to be meaningful to use. Besides taking into account the diversity of abilities that characterizes this population, it is also paramount to include them in the overall design process, which has been acknowledged in many previous efforts under names like participatory design [129] [63], user centered [157] or co-design [209].

The other motivation that derives from the circumstantial socio-demographic context we are living today, which inevitably impacts the future of the citizen wellbeing, is the design of digital user experiences focused on senior people, in the field of Health IT. Starting with the foundation of how an Integrated PHR should be, this thesis is then concerned in conducting user research and testing with senior people as a potential user group of these platforms. More specifically, the work presented in this thesis aims to understand what are the particular needs of this group to use the system and evaluate their desirability of adoption.

1.4. Measuring wellbeing in Integrated PHRs

Currently, digital technologies are still working on a driving shift to include wellbeing in the design process. However, technology has neither sufficient experience nor appropriate methodologies for dealing with the complexities of human wellbeing, requiring multidisciplinary research [21]. In what concerns to senior people, the awareness of their wellbeing is proven to be beneficial to this group but again, its measure and consideration is often overlooked by the design cycle of technology [69]. A comprehensive geriatric assessment is a clinical tool that helps providers to determine an older person's physical, mental and social functioning. Essentially, it gives providers a holistic view over the several dimensions of the individual's integrated health, but mostly, how they impact wellbeing. There is an urge for these assessments to become a standard practice in the healthcare system as they not only promote coordinated care but have also demonstrated to improve outcomes in the individual functional state (reducing unnecessary hospital admissions) [158]. Some technological applications may already provide platforms for such assessments but they need further design research and user validation [192]. When it comes to design an Integrated PHR with senior people in mind, studying and adapting geriatric assessments for wellbeing, is an important feature to be included in the system. As it is patient self-oriented, visual representations should promote self-reflection and be represented in a way that can be easy for seniors to interpret their data. Furthermore, the design of this feature has the potential to leverage collaborative reflection between the providers and seniors, who together, can elaborate an actionable plan for the senior to follow, through the use of the Integrated PHR.

1.5. The design of Integrated PHRs for Senior Telehealth environments

A literature review to assess the effectiveness of technologies applied to assist seniors, highlighted the major age care problems, targeted by researchers [87]: dependent living, fall risk, chronic disease, dementia, social isolation, depression, poor well-being and poor medication management. While Health IT was shown to have good results in reducing social isolation and enhancing wellness, Telehealth was considered to be the only technology to assist seniors with chronic disease showing significant improvements in the prevention of health conditions. Moreover, sensor technology was also reported to improve fall risk among other benefits, with the potential to enrich Telehealth solutions. Initially, voice communication via telephone or radio, was used to solicit the opinion of a doctor in the case of an emergency, but the potential of telehealth (or telemedicine) was boosted by the widespread introduction of information technologies into the healthcare sector with the capability of offering new services [59] [200]. Home Telehealth is described as "the use of telecommunications by a home care provider to link patients or customers to one or more out-of-home sources of care information, education, or service by means of telephones, computers, interactive television, or some combination of each" [94].

Interestingly, older adults recognize the utility of Telehealth systems [40]. Also, it has been reported in several studies to date that they accept well technology, enjoy self-monitoring and home Telehealth increases their sense of security [17] [106] [148]. An increasing interest from individuals for aging in place, rather than in an institution, is another driving force that turns Telehealth into one of the fastest growing areas of healthcare provision [94] [162]. Likewise, the dissemination of Telehealth programs enables the urgent need for seniors to access timely acute care [170]. However, socio-economic disparities among this group need to be studied as they can affect the ability to use a system or device [144]. Alongside, guidelines and standards for the design of Telehealth monitoring applications should also be regarded under special consideration [106]. The availability of personal data obtained within Telehealth systems also supports the concept of a PHR [40], yet these have still made limited use of patients' access to medical records and the integration with community services.

Finally, the last research line of this thesis is to apply the Integrated PHR in a technological environment that can answer to an increased demand of delivery of care outside hospitals, moving health services into the patient's homes, helping senior people to age in place. We found Telehealth to meet this purpose.

All together, the presented motivations of this introduction, took this thesis to explore the following summarized, main goals:

- Promote coordinated and integrated care in Health IT by facilitating communication between the citizen and healthcare providers across the different healthcare environments through the use of an Integrated PHR.
- Define a design strategy for the Integrated PHR new model: merge in a unique system, care records from providers with self-collected data from the person, studying how both sides can be integrated.
- Support the citizen life choices with self-collected data from the Integrated PHRs and provide more patient knowledge to healthcare providers in order to support their care choices.
- Improve patient-provider relationship and patient engagement.
- Improve the user-friendliness service delivery of the healthcare system.
- Design a valuable, accessible and credible user experience for the senior's ongoing participation in the decision-making process of their healthcare and wellbeing through the use of an Integrated PHR.
- Study multidimensional holistic views for the senior wellbeing in a self-awareness approach.
- Apply the Integrated PHR design model in Telehealth as a technological environment that also promotes integrated care, enabling seniors to live independently in their homes.

1.6. Research Questions

From the presented research goals, three questions outline the work of this thesis as follows:

(Q1) How can we combine and represent health data from different sources, into Integrated Personal Health Records to improve the user experience of the citizen healthcare?

This research question focus on providing a contribution for the foundation of the Integrated PHR that aims to improve health communication, in people lives. To accomplish so, it is necessary to identify, according to literature review, which existing PHR features are relevant to the design model, which new features are needed, and how they should be designed. For a sustainable integration of these features, we need to understand which information can be complementary and which data relationships can bring insights for the decision-making in self-care. The goal is to give a full picture to the citizen about all interactions that are concerned to their health, over time, as well as to enable electronic healthcare service tools to easily manage those interactions (e.g., schedule an appointment). As such, the research will look at ways of combining self-collected data (observations of daily living) with data collected by providers (e.g., patient medical record) in order to shape the system functional analysis, information architecture and user interface design.

(Q2) Which PHR features are most effective in improving healthcare outcomes in senior people?

In the domain of human measurement based medicine this question addresses the analysis of PHR features that can be more meaningful for seniors to engage with. We found the following metrics to guide the goal of this question, accordingly: measurements need to be clear (the person can understand what it means); answerable (it belongs to the person); efficient (it respects the person's time); relevant (describes the person's experience); educational (related to the person's condition), harmless (doesn't make the person sad, anxious or symptomatic) and actionable (helps people to change and discuss their condition with providers) [67]. The features should include both qualitative and quantitative data. In qualitative, we will look at subjective data as an outcome of self-reporting tools for the physical, mental and social wellbeing of the individual. These involve the collection of the observations of daily living (ODLs) that may represent "sensations, feelings, thoughts and behaviors" [68]. ODLs can be related to the report of health events such as symptoms, concerns, sleep quality, mood, or ease of doing daily tasks. An example of tools to measure ODLs are patient diaries (e.g., symptom diaries) or geriatric assessments (reporting physical, mental and social functioning) that result on follow up care plans, according to the measures results.

In quantitative data, we will look at manual or automated logs that measure and track health such as blood pressure and falls. Tools for measuring objective data have the potential of connecting health platforms with sensor devices, providing real time information that may alert users and its providers for critical conditions.

(Q3) How can we create a valuable user experience that may enhance the senior's healthcare self-awareness, while simultaneously engage them to work together with their providers towards the achievement of their wellbeing?

Taking into account human factors, this is a broader exploratory question that aims to map the cognitive, psychological and social characteristics of senior people, their way of thinking, their motivations and emergent needs regarding the participation in their healthcare. We first want to know how data should be displayed to seniors according to their mental models. We will look at holistic views that can integrate patient generated data. We will also look at communication channels and healthcare environments that may support seniors to live independently in their homes. Finally, we also want to understand how far seniors wish to adopt an Integrated PHR.

1.7. Research Contributions

This section consists of an overview of the research work, presenting its contributions, and how it was documented in the structure of this thesis. The research work is divided into two parts, presented in the document respectively, as **Part 1** and **Part 2**. Each part comprises a use case study, with distinct project agreements, in cooperation with the Portuguese Ministry of Health. Each part led to the design and development of a prototype and is presented with the following structure: use case scope, research work, design methodology, user research, design model proposal, prototype development and results. Both prototypes followed a user-centered design process, diverging in user research methods that were applied according to the requirements of each use case. The research work was highly multidisciplinary and collaborative, involving the stakeholders of the projects as well as the final end users, on participatory methods during the design process.

Stakeholders included project managers, developers, physicians and nurses. Before the stages are presented, we describe a **Literature Review** in Chapter 2 and the thesis **Research Methodology** in Chapter 3.

The first stage consists on the design strategy for an Integrated Personal Health Record, presented in **Part 1** of dissertation. This stage collaborated with the Portuguese National Patient Portal that covers about 1.100.000 users (by the time of our study), with the potential of covering the overall country's population of nearly 10 million citizens. More specifically, the patient portal launched in 2012, combines an Integrated PHR, that served as a use case for this work, raised by **Research question Q1**.

The Portal takes part of a cross-channel user experience of the PDS - Portuguese Data Sharing platform. The PDS combines the Patient Portal with a Health Professional Portal that receives data from more than 370 institutions. The platform has been taking the first steps to avoid scattered electronic health records across the several Portuguese facilities from the National Healthcare System (NHS). The **Use Case Scope** of this stage is detailed in Section 4.1.

The Portuguese Patient Portal as a use case scenario, was an opportunity to develop the proposal of an Integrated PHR design model for the following reasons: (1) It allows patient data to be shared across all healthcare facilities of the NHS through the unique summary care record, reporting all interactions with the healthcare system. All providers who the citizen interacts with contribute to the summary care record enhancing team collaboration work, amongst them. (2) Gives the citizen the ownership of their data, by providing its access, as well to the summary care record populated by the providers (3) the citizen contributes with patient generated data to the providers of the NHS, improving patient knowledge in care decision making. (4) The portal supports the citizen in managing their health by the use of electronic services (e.g., schedule an appointment), self-tracking and educational tools.

In this context, the first main contribution of this thesis is the proposal of a foundational design model for Integrated PHRs, inspired by the study of the Portuguese National Patient Portal. The **Design Model Proposal** is detailed in Section 4.5. The proposal was also derived from an **Extensive Literature Review** that can be found in Section 2.8. The review was made on PHRs and Patient Portals, as this new model merges characteristics and features from both these systems. The review resulted on a collection of features, grouped by topics that emerged from previous studies, which itself, can inform other studies that contemplate the design of an Integrated PHR. This contribution involves the following achievements available in the corresponding sections, respectively:

> Which set of heuristics in HCI field, are most appropriate to evaluate healthcare applications. Section 4.4.1.

> What are the lessons learned with real users of a Nation-wide platform, from the study of their online behavior and interaction with the stakeholders from the teams of project management, development, marketing and customer support. Section 4.4.5.

> Understand what are the potential user groups of Integrated PHRs (what are their characteristics and engagement level with the system), which take part of a Nation-wide healthcare network, meaning that its diversity can cover the user profiles of other similar systems, widely or more locally deployed. Section 4.4.6.

> Contribute to the communication strategy of the Portuguese Nation-wide Patient Portal in its integrated context of the PDS, promoting the citizen awareness over the Portal. Impact in the communication public portal by contributing to the increasement of registrations. Section 4.7.

The second stage consists on exploring the design of an Integrated PHR (derived from findings of stage 1), within the scope of a Senior Telehealth Program, presented in **Part 2** of this thesis. This stage collaborated with the Portuguese National Senior Telehealth Program (Saúde 24 Sénior) that follows about 24.000 seniors over 70 years old (by the time of our study). The program launched in 2014, aims at identifying and preventing frailty, risk behaviors, minimizing social isolation, promoting healthy behaviors and contributing to a feeling of confidence among the seniors. The overall health status and both environmental and individual domains related to the wellness state of the individual are assessed through a bio-psycho-social geriatric tool. The program comprises regular follow-ups, shifting from weekly to monthly, conducted by nurses who communicate with the seniors through phone calls. The **Use Case Scope** of this stage is detailed in Section 5.1.

The goal of this use case study was to address **research questions Q2** and **Q3**, by exploring also the design and adaptability of an Integrated PHR (derived from findings of stage 1), in an assistive environment that can support senior people to preserve their autonomy, by living independently in their home.

As such, the second main contribution of this thesis is the design of a cross-channel user experience for a Senior Telehealth Program, combining phone, with an Integrated PHR over the web that also connects with a smartwatch device. The goal was to explore how pervasive technology could leverage the telehealth program, by providing to the service, the individual context awareness, monitoring and prevention of critical events. The **Design Model Proposal** is detailed in Section 5.6. This contribution involves the following achievements available in the corresponding sections, respectively:

> What has been the experience of the Telehealth Program, regarding what are the perspectives and concerns of the communicating nurses, seniors enrolled in the program and how physicians have designed the clinical framework; what are the interest of these stakeholders in adopting a complementary web-channel and how it can be shaped and integrated with the phone line. Section 5.5.1 and Section 5.5.2.

> How the web-channel with an Integrated PHR can enhance the outcomes of the program care delivery by aligning the goals of senior participants with the goals of the service providers; how the explored features of the Integrated PHR, focused on senior people, can enable users to reflect and take control of their healthcare and wellbeing. Section 5.9.

To conclude the introduction, the goal of this research is to contribute to the design, deployment and dissemination of Integrated PHRs in the field of Health IT and Computer Human Interaction community. By exploring strategies that can be adopted in the design of this new type of personal health informatics system, this work aims to take part of a transition process that is changing the way the healthcare system behaves today, moving towards the improvement of patient-provider relationship, patient engagement and integrated care. To accomplish this vision, the work is based on two use cases that wish to illustrate the design thinking for the demands of an increasing ageing population. The results of both studies can complement each other by its concept, and also by migrating data from one prototype to the other, covering the full potential of what an Integrated PHR stands for. The partnerships from this research led this thesis to participate in two projects from the Portuguese National Healthcare System, with the goal to have a positive impact in the senior community but also in the overall citizen public health.

1.8. Thesis Publications

The research described in this thesis is available in the following publications:

* Rodolfo, I., Silva, G., Correia, N., Duarte, C., Louro, C., Botelho., A. (2017). Assessing the Senior Bio-Psycho-Social Wellbeing: The Design of a Cross-channel User Experience for Assessing the Senior Bio-Psycho-Social Wellbeing (conference full paper, under review)
* Laranjo, L., Rodolfo, I., Pereira, S. (2017). Adoption of a National Personal Health Record in Portugal - Characteristics of the "‘innovators". In JMIR Medical Informatics (journal)
* Rodolfo, I., Correia, N., Duarte, C., Louro, C., & Almeida, R. Perspectives on User Experience for a Nation-wide Senior Telehealth Program. In Proceedings of the 30th International BCS Human Computer Interaction Conference (HCI 2016). (conference full paper)
* Rodolfo, I., Correia, N., Sousa, M., Sá, P., & Duarte, C. (2016, May). How Far in the Future will We Start From?: Interacting with the Stakeholders of a Nation-wide Patient Portal. In Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (pp. 899-909). ACM. (conference case study)
* Rodolfo, I. (2016). Improving the senior wellbeing through telehealth support and integrated care. ACM SIGACCESS Accessibility and Computing, (114), 49-52. (conference doctoral consortium)
* Rodolfo, I., Laranjo, L., Correia, N., & Duarte, C. (2014, October). Design strategy for a national integrated personal health record. In Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational (pp. 411-420). ACM. (conference full paper)
* Rodolfo, I., Laranjo, L., Correia, N., & Duarte, C. (2014). The importance of mental models in the design of integrated PHRs. In AMIA 2014 Annual Symposium. (symposium posters)

1.9. Thesis Partnerships

This PhD established two partnership protocols between the Department of Informatics NOVALINCS of Faculdade de Ciências e Tecnologia da Universidade Nova de Lisboa, with two organizations that are conneted to the Portuguese Ministry of Health:

* **Partnership with SPMS** - Serviços Partilhados do Ministério da Saúde (Shared Services of the Portuguese Ministry of Health), in the scope of the Portuguese National Patient Portal of the PDS – Portuguese National Health Data Platform (Plataforma de Dados de Saúde).
* **Partnership with LCS** - Linha de Cuidados de Saúde S.A., in the scope of the Portuguese National Senior Telehealth Program, *Saúde 24 Sénior*.

1.10. Thesis Collaborations

The research work presented in this dissertation, has also collaborated closely with the following independent researchers, research groups and universities:

* **Researcher Gonçalo Dias da Silva, MD**: Faculdade de Ciências e Tecnologida da Universidade Nova de Lisboa – Master student in Informatics Engineering, at NOVALINCS - Department of Informatics. Collaborated in his thesis "Sistema Web para Programa Nacional de Telemedicina" that resulted from the project "Saúde 24 Sénior online" in partnership of this PhD with LCS. Responsible for developing the prototype in the use case of this thesis "Portuguese Nationwide Senior Telehealth Program" (Saúde 24 Sénior).
* **Researcher Fábio Rito, MD:** Faculdade de Ciências da Universidade de Lisboa – Researcher at LASIGE, Department of Human-Computer-Interaction. Collaborated in the responsive design development of the prototype for the Integrated PHR model in the use case of this thesis "Portuguese Nationwide Patient Portal with an Integrated PHR" (Portal do Utente).
* **Researcher Liliana Laranjo, MD, MPH PhD:** Postdoctoral research fellow at the Australian Institute of Health Innovation, Centre for Health Informatics. Collaborated during her PhD from Escola Nacional de Saúde Pública da Universidade Nova de Lisboa in the research methods of

participatory expert review, extensive literature review and as an MD consultant in the design proposal of the use case in this thesis "Portuguese Nationwide Senior Telehealth Program" (Portal do Utente).

* **Universidade Sénior São João de Deus, Lisboa:** Senior University which collaborated in several studies of the research work presented in this thesis by helping to recruit seniors in the classes of Informatics.

* **Nova Medical School, Faculdade de Ciências Médicas**: Collaborated with Professor Carlota Louro and Professor Amália Botelho, as MD consultants in the second use case of this thesis "Portuguese Nationwide Senior Telehealth Program" (Saúde 24 Sénior).

* **NOVAhealth research group:** This PhD has established collaborations with other researchers between the academic units of Universidade Nova de Lisboa in the domain of health research, more specifically with Nova Medical School. This PhD has participated so far, in the following NOVAhealth workshops:

> Health Informatics Workshop in 29 Apr 2016, presenting "Improving the senior wellbeing through telehealth and integrated care".

> Second Aging Workshop, "Diagnóstico: da tecnologia ao cidadão" in 10 Nov 2014, presenting "Design Strategy for Integrated Personal Health Records: Its importance in the identification of multidimensional diagnosis".

Literature Review

This chapter begins by presenting what are the main healthcare system trends around the world in the scope of Health IT development and health information interoperability and what is the role of PHRs by explaining its definition, type of formats and history. Then, the review provides some examples of pervasive features and research directions of PHRs. This first part is followed by an analysis of devices and integrated solutions for senior people in the scope of assistive technology, how self-monitoring tools can improve the senior wellbeing and finally, what are the online accessibility needs of this group, having in mind the design of PHRs.

The end of this chapter provides an extensive literature review, presenting a collection of features that can form an Integrated PHR. This collection served as a framework in the design of the proposed solutions that are part of this dissertation.

2.1. Healthcare System trends

Along with aging, technological changes are felt as a way to assist, maintain and prolong life. The European commission is concerned about the challenges that arise from an aging population. Having senior people as a particular focus, it was created a "strategic implementation plan of the European innovation partnership on active and healthy aging", in conformity with the "Global Age-Friendly Cities: A guide". The goal of this plan was to find innovative ways to improve independent living and prolong life while to ensure that senior people follow prescriptions; to prevent falls; to support early diagnosis; help prevent functional decline and promote integrated care models for chronic diseases [214]. Innovation and information technology are crucial to manage the healthcare sector [215] [39] by helping to improve the quality of healthcare services while answering more accurately to the patients needs. Another trend around the world is to assume that patients own their health data. Both the European Union's Data Protection Acts and the US Health Insurance Portability and Accountability Act (HIPAA) state that patient's data are owned by the patient and not by the institutions [5]. Giving the patients the ownership of their data enables an easiest and more ethical way of sharing data with others. This way, we are moving towards a new paradigm in healthcare industry that focuses on patient centered care.

The United States has been strongly investing in Health IT solutions since the American Recovery and Reinvestment Act held in 2009, part of a nation-wide health care reform, where the term 'meaningful use' applied to Electronic Medical Records (EMR), emerged. Since then, incentive programs have been promoted by the US Department of Health and Human Services and supported by the health information technology policy committee in order to define the healthcare system operability in a broader view, while presenting innovative software development guidelines, encouraging the adoption of EMR throughout the US [194]. Some of the core objectives were to enable "the use of electronic messaging to communicate with patients on relevant health information" and "provide patients the ability to view online, download and transmit their health information". Meanwhile, discussions in the healthcare community have been raising several questions, especially from healthcare providers who are concerned with the impact that these changes will have on their work habits [185]. However, this vision will remain and promises even more patient control and engagement, having as main driver a collaborative patient care approach for example, by providing "patients with the ability to request an amendment to their record online (e.g. offer corrections, additions, or updates to the record) through a patient portal in an obvious manner". Additionally, the committee also revealed the wish to "advance the concept of an electronic shared care planning and collaboration tool that crosses care settings and providers, allows for and encourages team based care, and includes the patient and their nonprofessional caregivers" [190].

Australia has launched in 2012 a National Personally Controlled Electronic Health Record (PCEHR) system that follows the same goals than 'meaningful use' to enhance their healthcare system. The PCEHR is aimed at connecting all participants and their interventions, and is intended to become a system-wide activity [139].

Europe is also going on the same direction, giving the first steps towards a strategy of continuity of care, interoperability and sustainability among the different European health systems. Behind the efforts to achieve an interoperable healthcare structure within the EU, the European eHealth Governance Initiative (eHGI) has supported the cooperation between Europe's member states and all the involved healthcare stakeholders in order to improve coordination and quality of care in Europe. This initiative was a result of the eHealth network, established by the Directive 2011/24/EU, published by the European Parliament over the disclosure of the patient's rights in Europe's cross-border healthcare [48]. In this context, one of the most relevant eHealth related projects was the "European Patients Smart Open Services" (epSOS), which aimed to "design, build and evaluate an infrastructure service that demonstrates cross-border interoperability between electronic health record systems in Europe" in such a way that seamless healthcare could be offered to all European citizens [177].

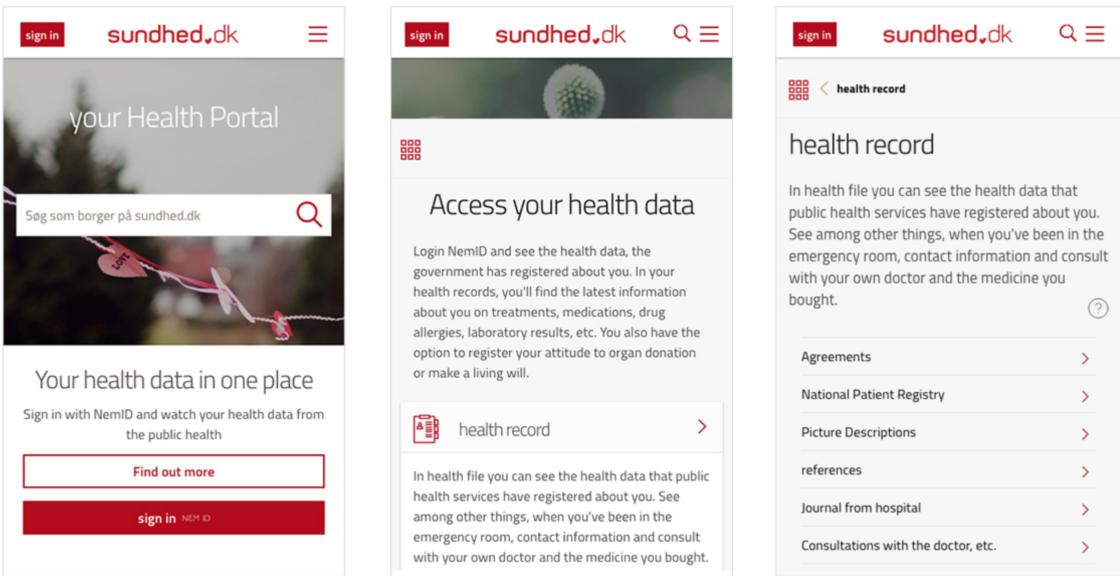

Figure 1: Danish eHealth Patient Portal.

The project had as main goal, enabling citizens the access to their patient summary record and e-prescription while traveling across Europe [51]. The integrated network that exchanges healthcare data between the EU countries is still growing among the several nations that have joined the project, such as Portugal. Considered to be a world pioneer in the digitalization of medical information, Denmark has released in 2003 the Danish eHealth public web-based portal (https://www.sundhed.dk/). This portal (see Figure 1) is one of the most advanced in the world [74]. Danish citizens can access their personal medical history since 1977. Besides the most common features like scheduling appointments, the portal has more advanced features such as preventive medicine, patient-to-patient dialogue in online patient networks, online organ donor registration and online living will.

2.2. PHR definition, formats and history

There are three types of electronic medical records: electronic health records (EHR), patient portals and personal health records (PHR). An EHR is "a set of records that clinicians control to coordinate their internal team work" while a patient portal "provides patients a view of the EHR of a single institution" and a PHR is "a set of records that the patients controls"[5]. PHRs have the ability to empower the patient, change and improve patient-provider relationships, enhance shared decision making and enable a more personalized and patient centered care approach while helping to decrease healthcare costs [9] [12] [71]. PHRs can be seen as extensions of the hospital healthcare activity, complementary with EHRs but more centered in patient inputs. There are three different models for a PHR [79] [43], a) Stand-alone (independent record that does not connect with other health information systems); b) Tethered (patient portal based on a health care provider's Electronic Health Record (EHR)); and c) Integrated (patient-controlled system that gathers information from multiple health-related sources, including the EHRs of independent providers). 'Meaningful use' requirements have fostered the concept that data should have a bidirectional flow between PHR and EHR systems through Integrated PHRs and not only EHR to PHR one-way [194].

Today, PHRs are typically web-based to improve deliver time savings and can be provided by several sources such as hospitals, physicians, healthcare organizations, private companies, employers or insurers. Most frequently they are either "patient-led PHRs", shared by the patient with their healthcare providers or "clinician-led PHRs", shared by the healthcare providers with their patients, being this last one the most likely route of mainstream adoption [5]. Hence, they have different results in content and format, since they answer to different approaches that depend on the stakeholders' data and functionality needs [127]. Continuity of care record (CCR) and continuity of care document (CCD) are both PHR data formats that correspond to a patient health summary standard, containing the most relevant and core health information about the patient which can be interpreted by any electronic medical record solution. For instance, Microsoft Health Vault uses the CCR standard to exchange data with healthcare providers and medical devices [5]. Besides engaging the patients in their own health, the major advantages of PHRs are: to allow better support to clinical teams, mainly in emergency situations; allow the privacy of data since its access is entirely controlled by the patient; allow patients and relatives to help providers in their work; enhance patient education; ensure the continuity of care.

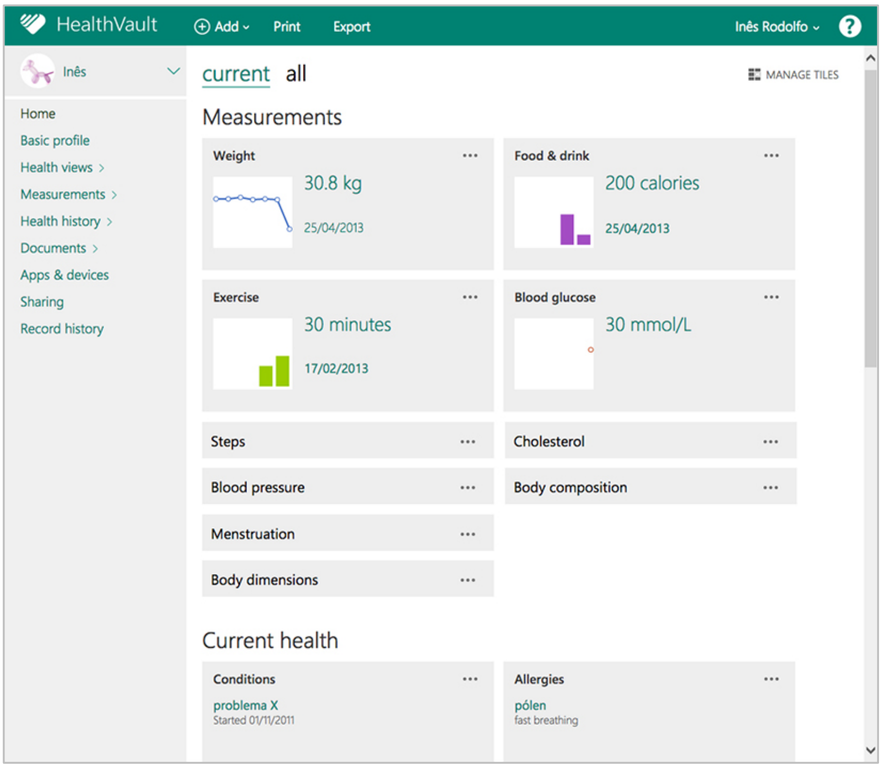

Figure 2: Microsoft Health Vault PHR.

Until recently, the use of PHRs by Portuguese consumers has been low whereas the United States has had a widespread use [89], nevertheless, 65% of healthcare consumers in Portugal are interested in using a system that would enable them to manage their healthcare information, check their condition and send tests results to their physician electronically [39]. Adults caring for older parents, especially daughters and daughters in law [20], and older adults themselves, tend to have the most interest on adopting PHRs [89] [9] [211]. This is because senior people often experience several problems at the same time such as chronic diseases, visual impairment, hearing loss, dementia and need healthcare systems to offer a safe care that goes beyond the hospital setting [215]. In what concerns to the PHR history and evolution, there are two dominant platforms that have emerged in the market: Microsoft HealthVault[2] (see Figure 2) and Indivo[3]. Google also released Google Health in 2008, though the project was soon retired from the market in June 2011.

2 Microsoft HealthVault: https://www.healthvault.com/pt/en

3 Indivo: http://indivohealth.org/

Some of the reasons discussed within the healthcare community explained that Google did not get the permission to share health data across institutions due to the US healthcare providers lack of commitment. Also, Google strategy did not considered a community of third party developers that could attract more users and contribute with valuable data to the platform through new applications [208].

Indivo started in 2006 as open source software, and is considered to be the pioneer and longest standing PHR in the Health IT industry accessible around the world. The Indivo's platform was initially developed by Harvard Medical School and applied on a small scale at the MIT's Children's Hospital in association with Hewlett-Packard, part of a study about flu vaccination, which aimed to test new concepts on patient-control health record systems [161]. Later on, Indivo was adopted by Dossia, a PHR service founded in 2006 by some of the large employers in the US such as AT&T, BP, Intel and Walmart, becoming one of the largest PHR deployments, used by millions of people in the world, releasing their API in 2009 [120]. On several research results, Indivo has reported early experiences with personal health records [65] or the integration of "personally controlled health records" (a subset of PHRs) with EHRs, based on patient ownership and access control of their data [113]. More recently, Indivo evolved to a platform that may be applied to any type of mobile or web application called Indivo X, which has the following architecture principles: "liquidity of data" and "built on open standards [194]. Moreover, the company has also created the SMART platform that stands for "substitutable medical applications, reusable technologies" which suggests that EHR platforms should support a selection of "substitutable" modular third party applications [112].

Benefiting from Indivo's open source data and architecture principles, Microsoft released HealthVault in 2007, a healthcare oriented platform that supports data interoperability and allows information to flow across multiple applications, having the ability to connect with sensor devices [121]. The advantage of Microsoft solution is the ecosystem and the information-sharing model that allows developers, solution providers, healthcare organizations and device manufacturers to easily create new apps on top of the platform. Additionally, according to the citizen's permission, the stored clinical information can migrate and be re-used across multiple applications and supplemented by several types of devices.

In what concerns to patient portals, Kaiser Permanente[4], Geisinger Health System[5],

4 Kaiser Permanente: https://healthy.kaiserpermanente.org/

Hello Health[6] and My HealtheVet[7] offer interactive solutions that enable the patient to access the EHRs mostly to arrange appointments, order medications or pay bills [5]. My HealtheVet was firstly released in the US in 2003 for the US veterans (25 million approximately) by the Department of Veterans Affairs (see Figure 3). The goal of this portal is to complement healthcare services, improve managed care and empower the patients and their families to become more active in the veteran's healthcare.

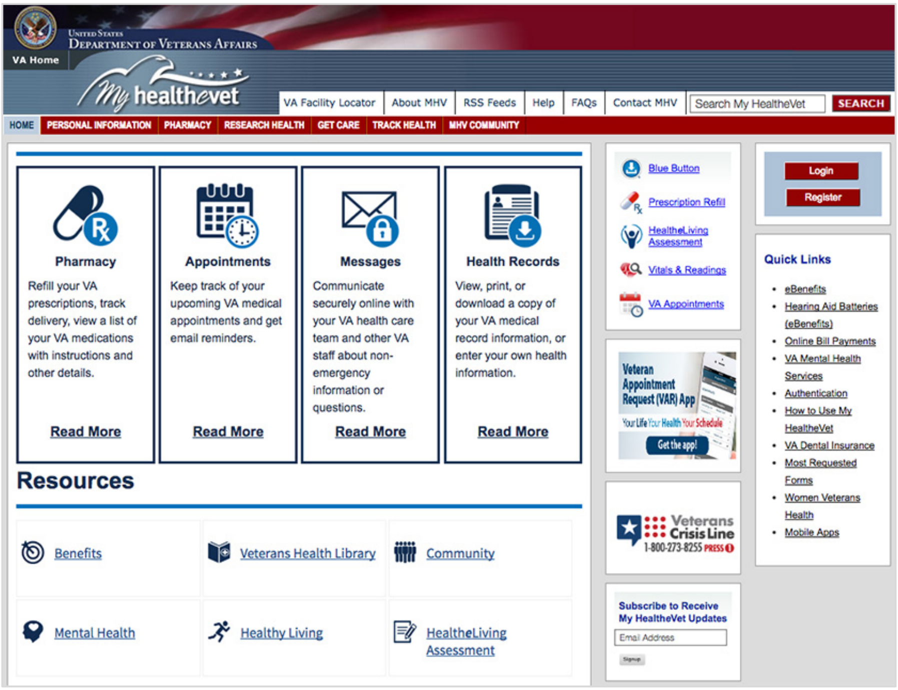

Figure 3: My HealtheVet Patient Portal.

The portal has several features that contributed to the design history of patient portals such as patient health education, comprehensive personal health journals and electronic services like e-prescription. By October 2009 the number of registered users were 850 000 representing 16% of the VA patients, reaching more than 32 million of visits [127]. An "American Customer Satisfaction Index" (ACSI) was applied to My HealtheVet in order to identify the portal user's characteristics, needs and preferences covering respondents aged mainly between 51 and 70 years. As main results, the highest satisfaction was regarding the content, functionality, look and feel and site performance. On the other hand, the need for further developments focused more on creating strategies to enhance computer literacy and

5 Geisinger Health System: https://www.geisinger.org/

6 Hello Health: https://hellohealth.com/

7 My HealtheVet: https://www.myhealth.va.gov/

usability, also suggesting additional desired services: 87% of the users named the possibility of visualizing the upcoming appointments; 74% to schedule or change appointments; 73% to look at information in the medical record and 64% to have online secure communication with their doctor [127].

More recently, Patients Know Best[8] (PKB), a patient-controlled record system founded by the physician Mohammad Al-Ubaydli, was considered to have success within the UK, winning the first place in the "Health 2.0 Europe's Competition" in November 2012. The system takes part of the NHS Connecting for Health network in the UK and is being used by healthcare providers in several hospitals such as Great Ormond Street Hospital, UCL Hospital, St Mark's Hospital, Torbay Hospital and other institutions across the UK having also been tested already in the US. The strategy of this PHR is to defend that patients should be the ones in control of their medical records. The citizens are seen as full owners of their healthcare data having the opportunity to fix errors, eliminate unnecessary appointments and treatments and be empowered by managing their own health. PKB believes that the patient digital records should not be architected around any particular facility as that may lead to problems in the coordination of care. Instead, the ideal is to have a PHR centered in the patient, dynamically enough to connect the several stakeholders that interact with the citizen. Hence, PKB focus on collaborative healthcare by enabling functionalities that allow teamwork such as providing the access to healthcare providers to see the full list of specialists dealing with each patient and be able not only to contact them, but also to see the discussion notes.

Another core functionality is to allow institutions to collect valuable data through semi-structured questionnaires conducted with the patients between the appointments on a regular basis. Regarding emergency situations, PKB have also designed a solution that consists on a bracelet device to be used by the patient, which allows important medical information to be kept and accessed by the emergency services in critical situations, e.g., in case the patient gets unconscious. This platform enables as well the opportunity of developers to create new web solutions.

8 Patients Know Best: https://www.patientsknowbest.com/

2.3. PHR pervasive features

Currently, PHR technology contemplates pervasive features within the scope of pervasive computing, allowing patients to collect valuable data or be merged with social media applications. Patients are invited to share and compare their healthcare experiences online by exchanging information with a wide community of people with the same health problems or concerns, e.g., people sharing the same disease or treatments. Based on the new paradigm of "Health 2.0", Patients Like Me[9] is a healthcare social network (see Figure 4) that meets this experience integrating not only PHR features, but engaging the users as well, to share their experiences in an online community [194].

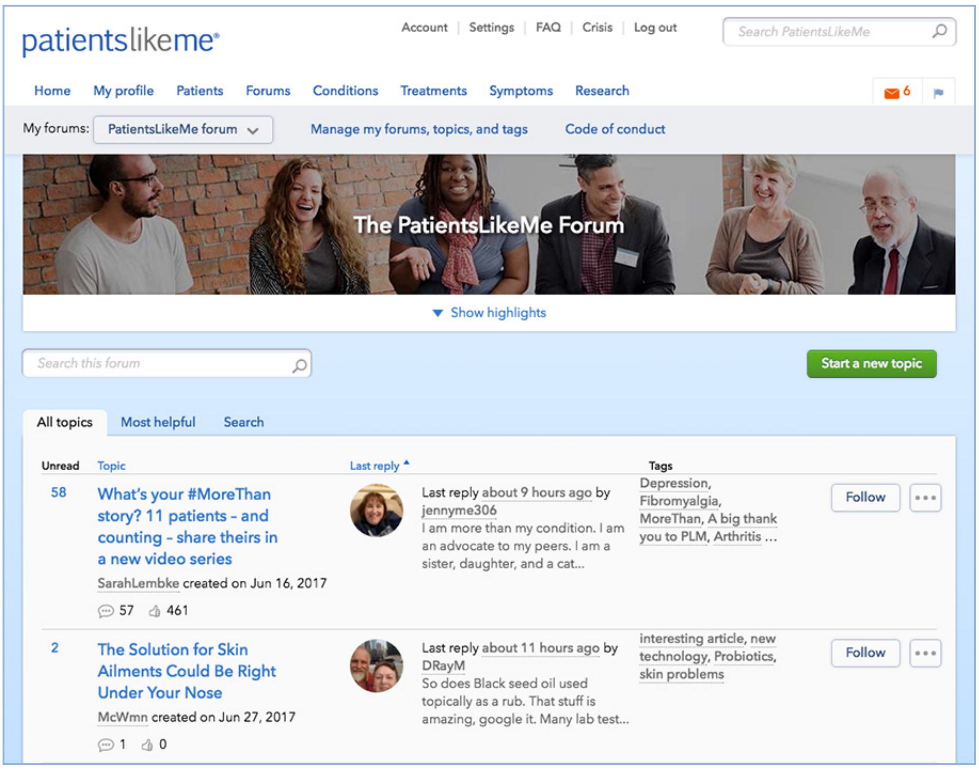

Figure 4: Patients Like Me healthcare social network.

The platform provides several self-tracking tools that can be used to identify behavior patterns such as mood diaries that show the user mood changes over time, according to tags of feelings or quality of life assessments. According to the platform co-founder, Jamie Hoeywood, human-measurement-based medicine is as a reliable way to track the severity and impact of a condition to support patients on making life choices and simultaneously, help physicians in their care choices, and provide researchers clues to determine what works best. Moreover, if measurement

9 Patients Like Me: https://www.patientslikeme.com/

becomes part of the care process, physicians can predict efficiently how a patient will do, what works best for that patient and how future patients can benefit from previous care cases [67]. Other solutions offer alternative types of documentation like Reliefinsite that visually tracks and documents pain [5]. An information system called PROMIS – Patient Reported Outcomes Measurement Information System allows healthcare providers to understand what is the patient experience. PROMIS provides dynamic tools to measure health outcomes from the patient's perspective, measuring self-reported health status for physical, mental and social wellbeing, by asking structured questions to patients [153].

Pervasive computing allows the interaction between human and computers to be natural while collecting valuable data from the living environment. From the group of the health and wellness devices, comes the term of pervasive healthcare that relates to patient context awareness, monitoring and response to emergency and critical situations [3] [201] [85]. Hospitals and other healthcare facilities are becoming ubiquitous environments by having different types of computer networks physically scattered in its spaces and wards as a way to enhance the quality of care [92] [174]. Due to the healthcare professionals mobility need, mobile communication or cloud-based services with PHRs are flexible solutions to access the patient's data anytime, anywhere [122]. People usually like to use their mobiles to receive test results for its fast delivery and because mobile devices are felt as a private media [5].

Mobile applications have the ability to connect and read information from biomedical sensors. Today, mobiles are the most common used devices in the world (used by 3.6 billion people), overlapping the use of computers e.g. when accessing the web, and considered to be "the first always-carried mass media" [56]. This is a consequence of mobile devices becoming computers (smart-phones) with rich functionalities interacting with multiple utility applications [4]. The ability of providing context-awareness through GPS location and sensors connection, along with the affordance of portability makes mobile devices a potential platform to deliver pervasive healthcare solutions for seniors. Actually, mobile phones and TVs are the most comfortable and used media by seniors as they already take part of their daily lives [60]. As an example, having senior people as target users and considering the fields of HCI and UX for mobile and future devices, Fraunhofer research center[10] has been developing pervasive solutions such as the ability to

10 Fraunhofer research center in Portugal: http://www.fraunhofer.pt/en/fraunhofer_portugal/home.html

detect lack of physical movement in senior's daily life by tracking the user's activity level on an mobile application; detect human falls and send text messaging warnings; collect data from medical sensors and schedule vital signs alarms; explore cross channel experiences in the scope of ambient assisted living such as connecting TV, mobile, desktop and home sensor systems.

2.4. PHR research directions

The earliest mention of the PHR term was in June 1978 in an indexed article by PubMed, being actively discussed in the past 12 years, through scientific articles of the scientific community [111]. A paper published at the end of 2008, collected several references about the existing research focused on PHRs, according to the PubMed database, to report the scientific evolution over this topic. While searching the term "personal health records" and "PHRs" since 1950 to 2007, 100 citations were found [79]. However, while searching by the terms "clinical decision support", the result was 17, 396 citations. When focusing on the first search, the 100 citations were mainly concerned to "PHR Function Evaluation", "PHR adoption and attitudes", "PHR Privacy and Security" and "PHR Architecture". Regarding the adoption and attitudes, the research found was mainly focused in specific populations including the elderly and patients with chronic illnesses, showing concerns on how the adoption of PHRs by these populations can be improved, having in account attitudes, usability testing, patient education, health literacy and accessibility. Other concerns were focused on structural features questioning if PHRs should be tied to EHRs versus stand-alone solutions.

PHR adoption and attitudes influence the design process [71] [114], as design should support the healthcare information needs of the patients, the work of healthcare providers, and the communication between both. More recently, PHR literature has been exploring the concepts of meaningful use, active aging, patient empowerment and engagement considering comprehensive information sharing, healthcare collaboration, cross channel healthcare experience and interoperability data. Patient privacy remains a common concern amongst the majority of papers. Several papers suggest that the design of PHRs should be user-centered [224] [210] [202] [182] [114] [71] and that the users' health information and functionality needs should be able to reflect the everyday life healthcare experience [19]. The Project Health Design part of a program supported by Robert Wood Johnson Foundation, applied a user centered design process to create Health IT tools having examined how PHRs applications and devices can integrate observations of daily living (ODLs) [152]. The project consisted on a design research challenge to envision PHRs as a platform for action, considered to be the most extensive user centered design documented to date in the evolution of PHRs. One of the main conclusions was that PHRs applications reveal a greater need for qualitative data represented by ODLs which represent “sensations, feeling, thoughts and behaviors”, than for quantitative data (static clinical record data) [19].

Part of the literature reveals the perspectives of patients regarding who should have access to their PHR; who should have permissions to add information [32]; how information should be shared [23] and which factors may influence patient participation and engagement [37]. More related to content and health generated data, patients expect content to be comprehensive and patient-friendly [71] [104] [218]. On another hand, the perspectives of healthcare providers reveal concerns and barriers in the adoption of PHRs such as privacy and patient generated data concerns. They question which content should be shared and what types of patient generated content can help them to assist their work e.g. how those records may assist them on planning interventions [71] [172]. Moreover, some papers reveal that healthcare providers have different needs on how to interact with PHRs according to their specialties. They value different types of information and expect that information can be displayed in ways to support knowledge discovery like comparing results and be able to visually “map out” possible content connections regarding what is causing a health problem [71]. Likewise, it is necessary to explore as well the design of health data by specialty and how the different displays can be integrated into the complex existing healthcare systems.

Some solutions already invite patients to access electronically the notes provided by the physicians after a visit. One study evaluated the effect of facilitating the patient access to the doctor’s visit notes, both on doctors and patients, promoting the vision of transparency within the healthcare experience field [38]. This study consisted on a quasi-experimental trial of primary care physicians and patient volunteers in a yearlong program that measured a portal use and its electronic messaging. Participants were surveyed about their perceptions over behaviors, benefits and negative consequences of the portal access. As a result, most patients reported that the ability to read the notes of their doctors was beneficial whilst doctors reported little or no impact on their daily work time, patient anxiety or confusion, as they initially feared. Nevertheless, doctors felt that communication with patients had improved and that shared decision-making increased patient satisfaction. Patients mentioned that they felt more in control of their situation by understanding their plans for care and get better prepared for future visits. Also, 80% said that the notes of their doctors helped them to take the medication more accordingly to the instructions. Another conclusion is that most patients and doctors agreed that patients should be able to grant other caregivers access to the notes. Finally, physicians are advised to write in a patient-friendly way, to write objectively (specially for bad news), avoid abbreviations and have separate notes (in paper) for private issues that the patient may share [5].

Research continues to be done regarding the adoption and use of PHRs by senior people. Several studies are being conducted to identify what are the most common barriers of the adoption of technology by senior people like "technophobia", low health literacy, limited physical and cognitive skills [89] [219] [189] [105] [104] [132]; what are the perspectives of seniors over the usefulness of PHRs [148]; how they wish to participate in their own health; which information do they value, and how far they wish to participate in the healthcare decision making [166] [165] [36].

In this scope, research on gerontechnology interfaces is of major importance to better understand these difficulties and to give us new insights on how to train and motivate senior people to actually use technology [132]. Cognitive functions should determine how an interface is designed, e.g., how information should be presented to complete a task, or how communicating features should be displayed. For instances, the fact that senior people have a crystallized intelligence (refers to life experience) rather than a fluid intelligence (refers to reasoning and concentration), results on a wide lack of different needs this group may have, which are connected with their mental activities, education and genetic factors [8]. Therefore, the interface may radically change according to the attitude and aptitude, which depends on the diversity of the senior characteristics.

Health IT usability is especially challenging since poorly designed user interfaces may result on medical errors and as the success of health data exchange is particularly challenging [71] [114]. Nevertheless, some papers reveal there is still much research work to be done concerning PHRs, especially for senior people, due to the usability constraints that this group faces and because of the complexity that monitoring multiple and chronic conditions at the same time involves [89]. In order to enhance the online participation of senior people, it is necessary to understand their behavior and needs [8]. Also it is necessary to find strategies to motivate them to interact with rich Internet applications and to record their own content, having in mind social disparities. Motivational aspects should also consider ethical concerns, especially regarding to monitoring devices, which have to be fully understood and accepted by the person, before its use [132].

Future research is still needed to detail mental models of individuals and healthcare providers concerning what should be the roles of patients in their own care [189] and how those roles can be reflected in the PHR information architecture [79]. In order to adopt a single integrated record in the future, a promising PHR model is to apply Wikipedia's strategy: a web page that can be edited by an entire care team and the patient, showing the consensus of the group, being able to track changes and to revert to previous versions [5].

2.5. AAL technology for seniors

One of the greatest concerns of an individual while getting old is to preserve autonomy and age in place. Ambient assisted living (AAL) supports seniors to remain comfortable in their homes through technological devices [13] [60] [159]. These devices fall in the category of assistive technology focused on the social, cognitive and physical needs of senior people [140]. Assistive technology deals with safety needs like environmental motion sensing services [150]; social connectedness needs like communication technology (e.g., mobile, email and web); and health and wellness needs such as biomedical sensors and telehealth support [35].

The main benefit of telehealth programs for senior people is the ability to increase their confidence and sense of security [17] [106]. Telehealth evaluates at long distance, the physical and cognitive state of an individual, and may include mobile technology. It is based on the transmission of biometric information such as vital signs, electrocardiograms, and other symptoms for a central repository, by telephone or Internet. In some cases, additional technologies may be used such as Radio Frequency Identification (RFID) tags, remote video cameras or intelligent devices to control the condition of the patient.

Telehealth services can change the way providers manage their practice, their patients and their work processes, providing different delivery models for geriatric care. An innovative healthcare model that uses high-intensity telemedicine services to provide rapid acute care for older adults, without requiring them to leave their senior living community residences, showed that these services expand the options for older adults to obtain acute illness care rapidly, with minimal burden [170]. This model is based upon a protocol where after a call for assistance, a responsible nurse performs a telephone evaluation that triggers the patient either for a telemedicine care path (e.g., videoconference) or the traditional care path (e.g., urgent care center). This study reports that adopting, integrating and sustaining telehealth requires value for stakeholders to adopt this model of care. Potential incentives include obtaining more detailed data (than with telephone calls), improving the quality and continuity of care. The most used assistive devices of Telehealth for senior people are emergency buttons, fall detection devices and heart monitor devices, which have the ability to be connected with central service providers [7] [106] [93].

Figure 5: Philips eCare Companion, a telehealth app that patients access in a tablet and use to share information with their care team. The app connects to a weight scale, wireless Glucose Meter Accessory, Pulse Oximeter and Blood Pressure.

As examples of integrated solutions to be delivered in home care for seniors are GrandCare system[11] or Phillips for home Telehealth solutions[12] (see Figure 5). Both these providers enable systems to track in real time, vital signs measurements through wireless sensor connection; connect family and caregivers; and promote social engagement. GrandCare system controls not only health condition but also the behavior of the home environment (temperature, doors, action button…), available on several platforms according to the user: television channel and touch screens computers for seniors and several types of tablets for healthcare professionals and informal caregivers. Philips delivers several telehealth programs for complex care management, chronic disease management or readmission management, informed by psychological research.

11 GrandCare system: https://www.grandcare.com/

12 Philips solutions: http://www.usa.philips.com/healthcare/solutions/enterprise-telehealth/home-telehealth

Today, wearable devices are increasingly common, trendy, and are used as assistive technology, especially smartwatches, as they can be used on a daily basis to detect the impact of falls, monitor physical activity and detect emergency events. These wearables have the potential to support senior people, boosted by the fact that they remove the typical social stigmatization of specialized “senior wristlets” or wireless remote buttons for home emergency devices [108].

The advance of technologies allows sensors integrated in smartwatches to capture physiological parameters and movements, using accelerometers, gyroscopes, magnetometers and heart rate detectors that are becoming an important source for health data analysis [143]. Heart rate, for example, is an important parameter in the detection of coronary heart disease because it provides information on functionality and efficiency of the cardiovascular system. However the accuracy of heart measurement is still far from the reliability of an electrocardiogram from the clinical setting, as this type of measurement requires a complex structure, difficult to be implemented in a domestic setting. However, a study that compared the performance of the LG G Watch R smartwatch heart rate sensor with the measurements of a PowerLab electrocardiograph and a CMS-60D oximeter, showed 90% correlation in the results obtained by the smartwatch and the other two devices [143].

Several smartwatch solutions have been studied to offer target-oriented features to the senior user group. The Digital Health Companion (DHC) system [193] is a smart health support system that combines research developments of activity, vital data, and anomaly recognition with the functionality of smartwatches. The monitoring of health in the system combines activity, vital data, and anomaly recognition technologies with default functions of current smartwatches, such as location tracking, push messaging, or phone calls, to allow for the usage of a stigma-free automatic emergency assistant. The study also addresses “permanent vital data extraction with smartwatches” to allow the detection of health risks expecting to be used as a reliable support and medical tool.

Another solution, developed for the Samsung Gear™ S smartwatch, tailored to an ambient assistance system [108]. The application covers a divergent target group by identifying different needs according to age. While younger senior people typically search protection by the app against sudden accidents during activities practiced alone such as leisure or sports, for older people the main interest is support in coping with age specific diseases focused on a more continuous follow-up. The common core of support functionalities for the application are: (1) Communication: manual calls for external help. (2) Orientation: Information regarding the current time, day of the week, date, month and year as well as holidays, birthdays of the smartwatch wearer and his relatives. (3) Localization: handles home needs requirements, for example, when leaving home, the application automatically issues a command to a home automation system to power down still active loads (e.g. electric stoves). Also, when the wearer leaves an agreed vicinity around his home, a situation not infrequent in the presence of dementia, the wearer will be tracked and get increasingly obtrusive advice to return to his home. (4) Detection of health hazards: based on the detection of activities and events of daily life by measuring if their duration is excessive or low as well as substantial deviations of the used circadian rhythm.

The application also continuously looks for tumbles and monitors the regular fluid intake by the smartwatch wearer. The user interface design presents a single display screen (no swiping or scrolling) and simplifies user interaction by giving limiting app inputs to either press an affirmative button for a presented issue or provide yes or no single choice in favor or against a presented question. The interaction with the app is also multi-modal including speech or gestural interaction.

2.6. Self-monitoring for the senior wellbeing

Prior evidence shows that senior people accept technology and are favorable towards self-monitoring their health data, [94, 106] [127, 148]. Nevertheless, further research is still needed to identify which components that are related to their health can better persuade them to adopt self-monitoring tools, which necessarily involves the analysis of wellbeing or wellness, a more holistic and complex concept. Dunn introduced the concept of wellness as "an integrated method of functioning, which is oriented toward maximizing the potential of which the individual is capable, within the environment where he is functioning" [41]. According to Dunn, a person finds ways to function at a high potential within an ever-changing environment. Acknowledging that the individual inevitably suffers from physical decline at some point, Dunn highlighted other factors to assess and improve wellness in older adults within their family and community living by following integrated assessments of internal and external factors of the individual. Since Dunn introduced the wellness movement, several researchers have been exploring holistic views over the concept. Kahneman has also approached the need for measuring longer-lasting characteristics of the individual by developing measures of wellbeing through self-reported assessments of one life satisfaction. Measures of "Subjective Wellbeing" (SWB) based on self-reports about global life satisfaction and affect, have become widely used [19, 80] (foundations of hedonic psychology). Moreover, one of the theories of wellbeing most readily applied to a technology context, in part because it is relatively straightforward, is Self-determination theory (SDT) [21, 143]. SDT posits that Autonomy, Competence and Relatedness are the key components of achieving wellbeing. In order to be self-determined, the individual must feel autonomous; confident in his ability to meet challenges and feel secure and connected to others. This theory is particular useful when applied in the design of applications for senior people as it gives particular importance to intrinsic motivation and autonomy.

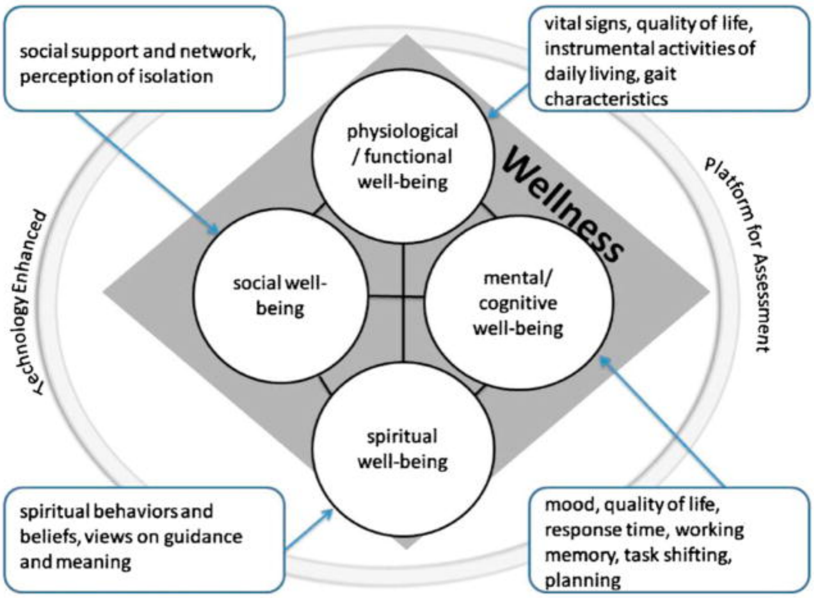

Figure 6: The framework for a technology enhanced assessment of older adults' wellness based on Hoyman's wellness model.

Since these theories emerged, self-tracking tools focusing on senior people have been developed to collect data related to wellbeing to provide a broader and integrated view over the person. One way of measuring the senior wellbeing is though geriatric assessments that provide a holistic view over the person. The results of these assessments should be carefully displayed to the individual through integrated visualisation techniques. Demiris et al. (2013) [41] demonstrated how Health IT applications can support the assessment and visualisation of older adult's wellness. They demonstrated a project pilot in an assisted living facility where a community room has been converted into a living laboratory for the use of diverse technologies to assess the multiple aspects of wellness of older adults. The used technologies include a telehealth component to capture vital signs and customized questionnaires, gait analysis component and cognitive assessment software. The purpose of the research was to present a theoretical framework to examine wellness holistically and how its several dimensions interrelate. The framework was based on Hoyman's wellness model (see Figure 6) that suggests four dimensions to examine the whole person in their environment: (1) physical wellbeing / fitness, (2) mental and cognitive health, (3) social wellbeing, and (4) spiritual wellbeing. Findings from the study indicates end user acceptance by older people and highlight the potential of integrating the reported wellness information in PHR applications to be used by older adults themselves but also their families, formal and informal caregiving networks.

2.6.1 Visualization techniques

Related studies explored visualisation techniques to display integrated health and wellbeing of older adults, which can be incorporated into PHRs. In a sudy conducted with older adults [99], diferent visualizations for wellness assessments were evalutated with focus groups (see Figure 7).

Figure 7: Radial plot representation of holistic wellness for older adults. Social, physical, cognitive, and spiritual components of wellness are modeled.

Conceptually, older adults found the visualizations valuable as a resource to stimulate discussion with their healthcare providers. The framework of wellness was favorably received as older adults agreed that wellness is a multidimensional concept. However, a personal level of customization was also requested given that individuals place different weights on social, spiritual, cognitive, and physiological wellness. In the study "Integrated data visualisation: an approach to capture older adults' wellness" [97], the goal was to test visual alternatives with a sample of senior users that focused on reducing cognitive load of data interpretation. This work expanded on a prior investigation involving the use of health monitoring tools within an independent and assistive living facility [192], which have demonstrated the feasibility of applying health assessment tools within an older adult community.

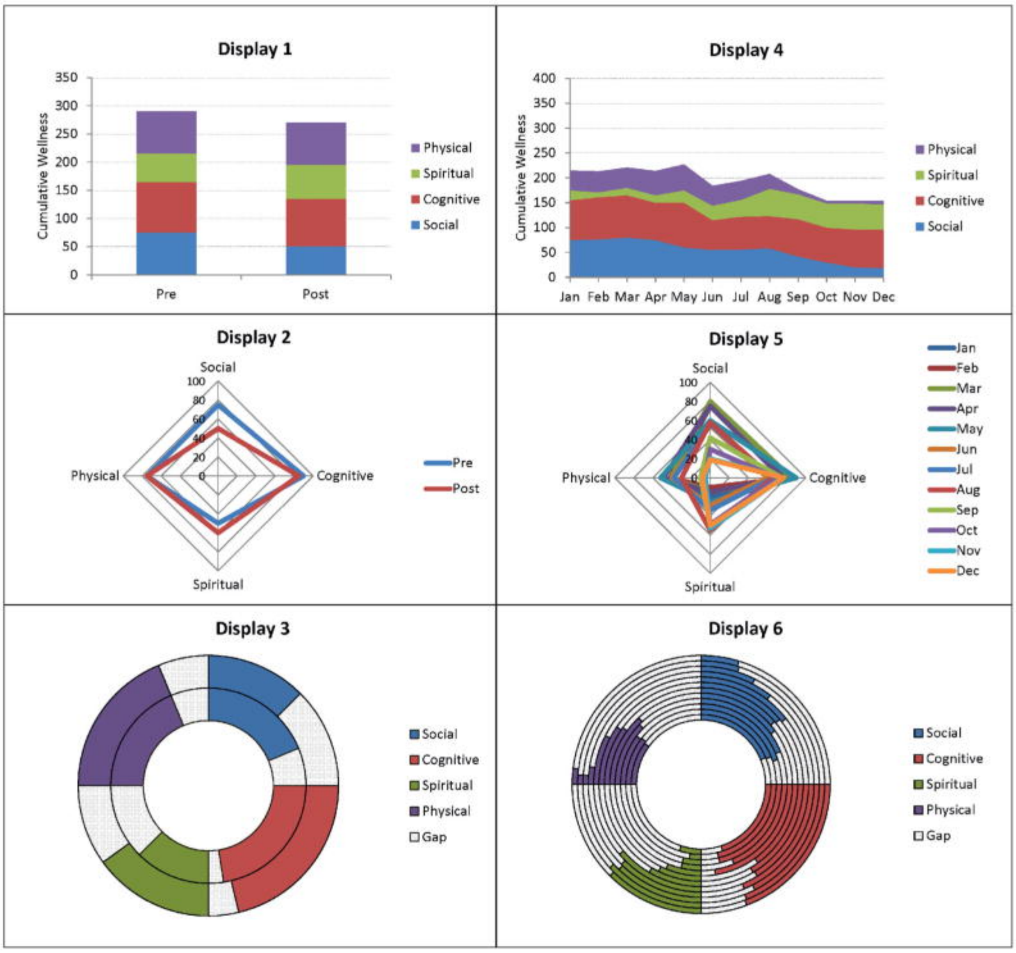

Figure 8: Three visualisation techniques for the assessment of integrated health and wellbeing of older adults.

The proposed visual design demonstrate distinct approaches to visualize complex longitudinal health related data sets, which included a stacked bar chart (see displays 1 and 4 in Figure 8), a wellness polygon (see displays 2 and 5 in Figure 8) and partitioned donut (see displays 3 and 6 in Figure 8). Among the findings, while stacked bar charts provide a simple display of information that is familiar to most users, comparisons across stacks involve increased cognitive load since the visualisation did not align stacks along a common scale. On another hand, the wellness polygon allows users to identify changes in components of health (as differences in the location of the vertices), though being limited when extended towards longitudinal comparisons and distracting. Finally, the partitioned donut, which presents the longitudinal data in a series of bands, allows for the examination of trends in each component, an improvement over the polygon techniques. However, it shows a higher cognitive load than in either of the two other approaches, due to the distinct separation of components in the donut.

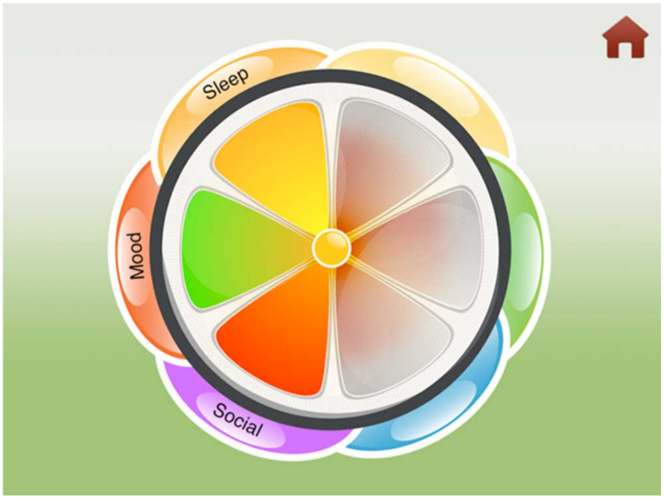

Figure 9: YourWellness feedback wheel with each segment representing a parameter of wellbeing.

Applying a more preventive approach, Doyle et al. (2012) designed [46] and evaluated [47] YourWellness as a self-monitoring tool to be used by seniors on an iPad (also available as a web-based application) engaging them to become aware of their wellbeing. The purpose of the research was to design and implement a tightly knit, closed-loop feedback mechanism to deliver wellbeing interventions to the older population, which includes support for emotional wellbeing. The system records the emotional status, quality of sleep and quality of social interactions, identifying its trends over time. Each time the user accesses the application, they can answer a short questionnaire with questions that assess their level of wellbeing. After submitting the answers, different scores are calculated and assigned to each of the wellness components displaying to the user a chart that represents their wellbeing, using the results of the previous 7 days.

The chart (see Figure 9) consists of a wheel divided into a number of segments equivalent to the total number of components that have been assessed. Each of the segments may appear green if the result is positive, or tend to a more orange color if the trend is unfavorable to health. When represented in red color, urgent intervention is required and a notification is sent to the providers. Findings of the research revealed that making seniors more aware of their emotional wellbeing would be beneficial. Furthermore, they also suggest on how to design for wellbeing. As an example: "long-term adherence is likely going to be achieved by keeping the application personal and 'fresh' – i.e. ensuring questions and feedback are not repetitive, are engaging and introducing something new each day, such as an interesting quote, joke or trivia question." [47]. Other features of the application are related to educational content, and strategies to improve health.

2.7. Seniors online accessibility

When considering a web-based PHR solution to be used by senior people, it is essential to understand their online experience and behavior and to address accessibility needs. The human aging process, is associated with vision decline, e.g., reduction of the visual field, hearing loss, motor skill diminishment and cognition effects, e.g., loss of memory, mood changes, confusion and communication problems [197] [207]. The following question rises in this matter: how do older adults use the web? Studies report that the primary reason for seniors using the web is the need of communicating with others, especially with their family [207]. Besides that, their online activities are much the same as the ones performed by younger people like seeking information or using online services.

Statistics show that in 2003, 32% of the American seniors were online, while in Europe 20% of the seniors had access to the web. Within Europe, France and Spain seemed to have less than compared with those in Sweden, where about 50% are online, the Netherlands, with 40% and the UK with about 29% online [24]. This makes older adults a fast growing group of internet users that not only use communication features, but also demonstrate other online interests such as health, financial and religious or spiritual information as well as shop online, make travel reservations and visit government sites [109] [197] [207].

In this context, the W3C has been working in the project "Web accessibility initiative: ageing education and harmonization (WAI-AGE)" which has as main goal, the promotion of web accessibility requirements for older adults with age-related impairments [131]. Having performed a literature review on this subject, WAI-AGE found 150 scientific and professional articles that were mainly focused on “discussions of the functional limitations often experienced as part of the ageing process”; “collections of broad recommendations for making Web sites more accommodating for older users”; “studies focused on particular limitations experienced by older users”; and “studies looking at specific design aspects of websites or specific types of sites” [8]. Afterwards, several guidelines from different authors were found regarding the design, usability and accessibility for senior people. These guidelines compiled several requirements from different sources and concluded that the majority of accessibility requirements of this kind addressed usability needs such as: content presentation, text size, spacing, justification, margins, contrast and colors. Problems that should be considered, were also identified such as overwhelming, hard to understand content; layout changing; navigation problems, e.g., with a non-linear path; too many choices or moving interface elements [8] [197].

When designing for senior people, the font size should be larger than usual (typically 14 points or more) and titles should be explicit. It is also important to have high contrast between the dark and light colors of the page. Given the difficulties of mutual concentration in text and audio, sound effects should be avoided. Pop-ups or animated images are discouraged by diverting the attention of the user [8]. Another study titled as “New heuristics for understanding older adults as web users”, reviewed 50 websites to learn how well they supported older users, concluding that websites designed to a wider audience, tended to fail because of the different ages and user abilities [24]. Consequently, the study suggests that the design of websites should consider foremost the audience diversity in what concerns to attitudes, abilities and skills of the users.

2.8. Extensive literature review

In order to support one of the main contributions of this thesis, that is to create a foundational design model for Integrated PHRs, an extensive review of the literature was conducted to collect features that could take part of this new model. Due to lack of literature over the functional architecture of Integrated PHRs (which origined the purpose of this collection), the review was made on PHRs (and all related systems) and Patient Portals, as these typologies provide characteristics and features that can be merged in the new model. The search of the literature was performed in PubMed, Embase, Web of Knowledge and ACM Digital Library. A combination of the following terms was used: 'Personal Health Record', 'PHR', 'Personally Controlled Health Record', 'PCHR', 'Electronic Patient Record' and 'Electronic Patient Summary'. An additional strategy included searching the reference list of the articles selected for review.

The screening of the studies was based on relevancy of the titles and abstracts (if they were focused on the description of system functionalities), and done with another independent researcher from the field of medical sciences who was also collaborating with the project. If a decision on inclusion or exclusion could not be reached by reading the title and abstract, the full text was retrieved. 1,047 papers were found in the initial search. After reading the title and abstract, 946 articles were excluded for not meeting the inclusion and exclusion criteria and 19 articles were duplicates. The most cited articles in literature were also identified [43] [79] [91] [189] [164]. The niche of our study targeted 82 articles from which an extensive review was performed in order to identify and list the most cited and innovative functionalities of PHRs and patient portals. From those 82 articles, 9 were excluded during the process as they did not focus on functionalities but rather on the characteristics, definitions and trends of the systems. Finally, we listed and organized the functionalities of PHRs and patient portals that were collected from 70 papers from the literature. A table was created with a structure that specified the functionality name; description; benefits; and bibliography identification. All functionalities were grouped in the categories that follow this section. Some features are more generalist and others, more specific. Each functionality checks in its title, if it takes part of the functional analysis that was created for developing the prototypes that compound this thesis, respectively for the National Patient Portal (first use case) the Senior Telehealth Program (second use case).

2.8.1 Electronic healthcare services

Functionalities that allow patients to be engaged with others regarding their healthcare data, e.g., patient access to electronic medical record from EHRs.

Patient access to their electronic medical record (EMR) / Summary care record

use case 1 ✓ use case 2 ✓

Description: Patients should be able to access their own medical record from healthcare institutions. The record should include documentation of medical care such as test results, patient problems, procedures, medications, allergies and provider notes, as well as registration and billing information.

Benefits: Improves care delivery and offers the patients better insights over their condition.

References:
[127] [81] [151] [18] [133] [68] [78] [135] [205] [54] [187] [147] [134] [194] [156] [137] [86] [213] [189] [10] [101] [50] [204] [79] [138]

Patient can offer amendments to the EMR / Verification of Patient Information

use case 1 ✓ use case 2 ✓

Description: The patient should be able to supplement incomplete information and correct errors of their medical records, imported from other sources. They should be able to add information such as notes and alternative treatments or edit existing one such as medication, problems, allergies or tests. The level of patient's amendments can vary across institutions/physicians opinion. It should be decided which information the patient can amend (such as symptoms or OTC medication use) and which information might depend on a previous request to the responsible medical professionals.

Benefits: This functionality improves safety, increases clinical efficiency and avoids possible treatment errors.

References:
[43] [68] [78] [187] [76] [194] [136] [137] [213] [189]

View doctor's notes

use case 1 ✓ | use case 2 –

Description: Access electronically to the physicians' notes after a visit (through a notification email message) These can be progress notes or visit summaries and should be written in a narrative form, in everyday language.

Benefits: This functionality enables benefits to the patient visit recall and care instructions.

References:
[[98] [151] [145] [116] [76] [137] [38]

Accessing test results

use case 1 ✓ | use case 2 –

Description: Retrieving of exams and lab tests.

Benefits: Access to test results is one of the core elements consistently described in most of the published evaluations that comprise the basic patient portal.

References:
[43] [151] [49] [68] [54] [187] [76] [137] [10] [101] [204]

Secure messaging with providers

use case 1 ✓ | use case 2 ✓

Description: Allows users to contact their providers as well as for the health of others for whom they are a proxy, for any questions about health and advices on illnesses that do not require an office visit. Messages can be sent to clinical groups enabling a broader discussion over any health issue about the patient. Secure messaging as part of the Portal/PHR web-based system (with an integrated message server) is more effective than an email communication. The personal email should only function as notifications for new messages. This way communication can also be easily tracked,

References:
[74] [81] [151] [49] [145] [18] [133] [68] [116] [78] [135] [205] [54] [187] [44] [76] [142] [134] [171] [136] [203] [137] [86] [217] [189] [9] [204]

managed, documented and evaluated inside the system.

Benefits: Secure messaging can improve patient healthcare and increase patient satisfaction. It is very useful to people with long-term conditions. Some patients are more comfortable with this type of communication, feeling less intimidate than face-to-face conversations and helps to decrease face-to-face visits, improving care time delivery.

Appointment Scheduling

use case 1 ✔ use case 2 ✔

Description: The users are able to schedule, change or cancel online appointments. The process of scheduling should allow patients to choose from a set of available visit times and dates in a calendar and be electronically notified regarding the status of its request. While scheduling new appointments, data fields can be automatically populated based on a historical visit.

Benefits: This functionality increases patient satisfaction and improves services scheduling efficiency and less staff labor time improving clinical outcomes.

References:
[186] [43] [189] [9] [127] [81] [49] [107] [18] [133] [68] [116] [78] [205] [54] [187] [76] [142] [134] [136] [137] [86]

Prescription refills

use case 1 ✔ use case 2 –

Description: Users are able to request medication refills and renewals as well as to check its request status.

Benefits: This functionality is very useful to people with long-term conditions who require periodic medication refills. It improves medication adherence and reduces clinics call volume and gives staff members more time to serve patients with urgent needs.

References:
[186] [127] [43] [189] [9] [81] [49] [145] [68] [116] [78] [205] [54] [187] [44] [76] [142] [134] [136] [137] [86]

Referral requests / self-referral

use case 1 –   use case 2 –

Description: The system can enable referral authorization requests. As patients become more informed about their health conditions and treatment options through patient education, they are able to start a referral process by asking their primary care providers to initiate them or seeking specialists on their own.

Benefits: PHRs/Portals can facilitate the referral process between patients and their specialists with the advantage that specialists gain a unique assessment of patients' medical problems, as they are collected in the patient's own words.

References: [9] [81] [205] [54] [187] [206] [136] [137] [189]

Healthcare Expense / Billing Tracking

use case 1 –   use case 2 –

Description: The system can offer the ability to track and manage healthcare costs, helping to process claims of payment. The system can provide expense organizers that allow expenses management by categories such as medications, visits or tests.

Benefits: Capturing cost information improves the understanding of healthcare expenses and increases healthcare services transparency.

References: [43] [81] [18] [133] [78] [54] [187] [76] [34] [142] [137]

Reviewing of insurance / healthcare system eligibility and benefits

use case 1 ✓   use case 2 –

Description: Support users in their interactions with insurance companies prodding forms for benefit claims. Financial benefits can be explained such as information about co-pays, co-insurance, amounts covered by

References: [43] [127] [145] [68] [116] [10] [205] [187] [76] [34] [142] [137]

insurance benefit, payment status and dispute information.

Benefits: This functionality provides a better utilization of health insurance plans and helps to decrease healthcare costs through a better understanding of health insurance coverage.

Advanced Directives and online organ donor registration

use case 1 ✔ use case 2 –

Description: The system should record the person's end-of-life wishes such as living will and organ donation.
Each advanced directive should have a date, circumstances under which the directive was provided (e.g. early stage of Alzheimer disease) and the location of any paper record regarding the directive if necessary. This also includes the selection of a proxy to manage the person's healthcare in case of incapacity. The proxy can then record the patient's treatment preferences.

Benefits: This functionality addresses healthcare services ethical concerns and assures person's wishes are fulfilled and respected in their end of life or in case of incapacity.

References: [186] [74] [127] [107] [116] [10] [136] [156] [86]

Waiting list information from hospitals

use case 1 ✔ use case 2 –

Description: The system should provide un online updated surgery waiting list information to their patients.

Benefits: Provides an updated status of the person's waiting position for an upcoming surgery, managing ones' expectations and relieving anxiety.

References: [186] [54]

Telehealth Remote health care delivery

use case 1 –

use case 2 ✔

Description: Enables patients to communicate with healthcare providers remotely from home. Telehealth is particularly useful for vulnerable people with long-term conditions that need a closer follow up. Telehealth technology employs ubiquitous computing technologies such as social media communication, home monitoring devices and mobile applications that can measure and storage and control the physical and psychological data from the individual, through biosensors. Enables the patient context awareness to their caregivers and family, monitoring, responding to emergency critical situations (e.g., elderly fall detection). One of the core features is videoconferencing that replaces in-person visits for online consultations with secure video with patients.

Benefits: Telehealth enables a more efficient use of time of healthcare professionals, allows patients with critical conditions or elderly people to stay comfortable in their homes and mostly, facilitates remote care of patients living in rural and remote location improving the quality of healhcare delivery.

References:
[86] [35] [11]

Pre-encounter and post-visit questionnaires

use case 1 –

use case 2 ✔

Description: Enables physicians to survey patients between, before or after visits. The system can supply patients with a range of forms and questionnaires that gather important clinical and/or administrative data to inform the caregiver.

Benefits: This functionality facilitates and improves the clinical encounter and care monitoring. A pre-visit

References:
[116] [78] [44] [76] [136] [137] [86] [204]

questionnaire improves the efficiency and quality of the visit while post-visit questionnaires provides patient feedback and helps to measure care processes.

Medical facility directory

use case 1 ✓ use case 2 –

Description: The system can provide a directory of institutions and providers allowing users to search for names, addresses, GP's contact information and enabling the comparison of prices, insurance protocols, quality and accessibility.

Benefits: Findability of healthcare services increases patient satisfaction and the healthcare experience.

References: [186] [127] [68] [205] [54] [187] [34]

Care plans

use case 1 – use case 2 ✓

Description: The physician can release care plans to the patients through the system. Structured care plans may contain health goals and steps for the user to follow, specific guidance to other caregivers, suggested orders and nursing interventions. Care plans should have the ability of being managed across several providers if needed.

Benefits: As patients are able to review care plans, they become well informed and more willing to undertake the provider's instructions in order to achieve health goals.

References: [211] [83] [68] [116] [78] [135] [76]

2.8.2. Patient Education

Interactive educational tools, patient organizations or health social networks.

Multimedia content

use case 1 ✔ use case 2 ✔

Description: Ability to access educational materials and best practices for both clinical and self-care healthcare information in/through the system. The user should be able to search lifestyle choices, medications, treatments and disease comprehension information. The information can either be routinely integrated in the system through reliable sources of patient education material feeds or either by clinician provided links that support patients and their families regarding given health concern, condition, diagnosis, follow up from a clinical visit, identify treatment options or any other healthcare needs.

This can result on a library of educational materials that are exchanged with the patients enabling the possibility, when appropriate, of documenting the patient comprehension about a given material.

Benefits: This functionality allows users to learn about their health while providing personal decision support to better manage themselves. Patient can better understand their diagnosis and treatment options improving quality and efficiency of care; lifestyle behaviors can be improved with better online education, e.g., diets, exercise. Patients can adhere better to medication.

References:
[127] [43] [91] [9] [127] [148] [151] [49] [95] [116] [78] [135] [187] [76] [19] [34] [134] [194] [136] [64] [84] [86] [204]

Medical knowledge support

use case 1 – use case 2 –

Description: Relevant health educational resources can be automatically linked to key terms or phrases in the patient's record to help the patient understand unknown medical vocabulary.

References:
[107] [203] [187] [84] [86] [164]

Benefits: Facilitate health communication with providers.

Providing illustrative images

use case 1 ✓ use case 2 ✓

Description: The system should provide illustrative images, grouped by health topics, when applicable.

Benefits: In addition to demonstrating complex usage scenarios, illustrative images and multimedia content can also generate an emotional response in patients emphasizing the importance of certain health actions.

References:
[107]

Health encyclopedia or glossary

use case 1 ✓ use case 2 –

Description: Information about health problems and treatments.

Benefits: Understand a given diagnosis and treatment options.

References:
[107] [203] [187] [84] [86] [164]

Healthcare support groups

use case 1 – use case 2 –

Description: Patient to patient dialogue in online patient networks. Links to peer support groups and online coaching.

Benefits: Users can chat about their common health concerns and exchange their experience or relevant information.

References:
[194] [43] [9] [107] [68] [78] [135] [187] [76] [34] [134] [194] [136]

Learn about opportunities to participate in medical research

use case 1 —   use case 2 —

Description: Learn about clinical trials where the patient is eligible to participate.

Benefits: Opportunity to access innovative treatments.

References: [136] [137]

2.8.3. Self-monitoring tools

Subjective self-reporting, objective monitoring via electronic devices, e.g., wearable sensors.

Patient manually-entered health measurements (objective data)

use case 1 ✓   use case 2 ✓

Description: The user can log manually and track health measurements such as blood pressure, weight, height, body mass index and blood glucose.

Benefits: Patient monitoring and chronic disease management can improve health outcomes. Related features include track daily goals and progress over time and share. Alerts for critical conditions and events.

References: [189] [9] [127] [151] [49] [68] [135] [141] [134] [203] [79]

Patient automated health measurements (objective data)

use case 1 —   use case 2 ✓

Description: The system can be connected to biomedical sensors and devices. Users can have their physical activity monitored by wearable devices while providing real time information to the caregivers supporting remote healthcare services such as telehealth.

Benefits: Improves patient monitoring and chronic disease management. Alerts for critical conditions and events.

References: [74] [42] [183] [68] [116] [135] [187] [44] [76] [34] [134] [194] [43] [189] [9]

Observations of daily living (subjective data)

use case 1 ✔ use case 2 ✔

Description: Users can enter subjective data to self-report health status for physical, mental and social wellbeing. The system can provide the ability to collect observations of daily living which represent "sensations, feelings, thought and behaviors" reporting healthcare events such as symptoms, concerns, pain experience, anxiety, sleep quality, mood, adherence and medication regimens, ease of doing daily tasks or even report a conversation with a caregiver. There are several tools that can report ODLs such as patient diaries that report qualitative descriptions of symptom, organizing the information chronologically; symptom and pain scores (reporting several factors e.g., levels, duration), quality of life score (reporting physical, mental and social functioning), feeling tags and surveys such as mood map surveys.

Benefits: Improves patient documentation and helps patients to identify health trends, patterns and aggravators resulting in better care planning and health decisions. Patient perspective gives clinicians new insights over the patient's health experience and evolution complementing clinical information and medical knowledge.

References:
[19] [189] [127] [49] [68] [116] [135] [83] [76] [19] [34] [134] [68] [203] [86] [213]

Health information lists

use case 1 ✔ use case 2 ✔

Description: Allows users to enter their health data such as immunizations, medications, problems, allergies and test results through structured information screens.

Benefits: Informs the user what and how to report health information in a structured way.

References:
[78] [203] [86] [10] [73] [90] [138]

Health assessments

use case 1 – use case 2 ✓

Description: Consist on structured surveys (with algorithms that calculate a result according to given scores of each answer) that measure the patient wellbeing or health risks. As an example, geriatric assessments evaluate the overall wellbeing of senior people.

Benefits: These assessments enable a better understanding of wellbeing factors and risk status empowering individuals to manage their condition and giving providers additional knowledge.

References:
[43] [49] [95] [68] [113] [205] [44] [84]

2.8.4. Information Sharing

Functionalities that help manage how health information is shared with other trusted parties.

Share information with others

use case 1 ✓ use case 2 ✓

Description: Users should be able to easily share information with whom ever they choose, maintaining privacy through safe access. These include family members or other informal caregivers. This functionality includes the possibility to share the profile with others by enabling the access to health information and use features on behalf of a family member. Manage how the records are shared with other trusted parties: enables audit control regarding healthcare providers interaction with the patient's data. Everyone wishing to view a patient’s record needs to acquire their consent in the system.

Benefits: Increases sense of security regarding privacy

References:
[43] [148] [18] [113] [187] [156] [10] [213] [86] [68] [137] [101] [79]

of data. Sharing data improves health communication and care delivery.

Print summary record for sharing

use case 1 ✓ use case 2 ✓

Description: Ability to print out a copy of the record, to take along during a visit to a physician, who otherwise might not be able to view them digitally.

Benefits: Improves portability of information when necessary in a visit.

References: [68] [187] [64] [86] [78] [91] [101]

Provide an emergency access "break the glass"

use case 1 – use case 2 –

Description: The system should allow an emergency view of the user profile. Create a "break the glass" option than enables providers under strict circumstances (e.g. individual is brought unconscious into an emergency room) to access the system. This type of access needs to be audited afterwards.

Benefits: Can offer important information to healthcare providers in an emergency situation.

References: [91] [187] [147] [34] [156] [86] [101]

Upload documents

use case 1 ✓ use case 2 –

Description: Provide mechanisms for incorporating external clinical documentation such as image documents and other clinically relevant data.

Benefits: Contributes to health documentation

References: [68] [116] [187] [83] [34] [86]

2.8.5. Patient support

Functions in the system that provide reminders, instructional or motivational feedback to support prevention and wellness management.

Intelligent recommendations and reminders

use case 1 ✓ use case 2 ✓

Description: Based on patient decision support, the system may interpret how the user is doing each day and according to his data history can provide personalized treatment recommendations. The system should provide reminders of preventive care informing whether to get a service and how often. Preventive reminders can include text messages, phone SMS or email notifications.

Benefits: Stimulate patient's decision making, reduce anxiety and help to prevent healthcare problems and critical situations. Increases patient knowledge of preventive guidelines and improves the performance of the physician.

References:
[43] [91] [127] [148] [151] [49] [107] [194] [95] [68] [116] [78] [135] [205] [187] [44] [76] [19] [34] [142] [134] [136] [84] [137] [125] [164] [217] [204] [79]

Health calculator tools

use case 1 ✓ use case 2 –

Description: Calculators are useful tools to quickly estimate the user's health status informing about physical data values and if they are in risk. They can offer recommendations and educational material.
Examples of calculators are: BMI calculator, calories needs calculator, pregnancy calculator.

Benefits: Provides the user a quick evaluation of his condition(s), and helps to motivate general wellbeing and fitness goals.

References:
[9] [68]

Providing interpretive information about laboratory test and diagnostic study results

use case 1 — use case 2 —

Description: Provide assistance for users to understand and interpret the providers data such as lab tests results, explaining if they are in a normal range or not. Automatically generate micro-explanations according to the user characteristics.

Benefits: Can help to decrease patient anxiety.

References:
[91] [211] [212] [84]

Specialized health modules

use case 1 ✔ use case 2 —

Description: Specialized sections that deal with certain health/medical issues such as "child health module" or a "diabetes module."

Provides calculators, recommendations, guidelines, and advice. Manages a chronic condition that requires close follow up.

Benefits: Helps the patient to manage a chronic condition on a daily basis, alerting for critical events, when necessary.

References:
[34] [19] [57] [68] [117]

Medication management / drug interaction checking

use case 1 — use case 2 —

Description: The medication module allows patients to view and modify the list of medications and allergies in the system, identify medication discrepancies, report no adherence, side effects and other medication related problems and easily communicate this information to providers. This functionality should also provide consumers with the ability to check a specific drug

References:
[43] [127] [116] [187] [34] [62] [174] [173] [84] [137] [164]

against his or her current medication list to check for drug-drug, drug-allergy interactions.

Benefits: Improve treatments and medication reconciliation.

Scheduler

use case 1 ✓ use case 2 ✓

Description: Schedule also other type of events besides the appointments, which are related to the management of healthcare, e.g., exams.

Benefits: Contributes to healthcare management.

References: [54] [19] [86]

Longitudinal tracking / display data and trends over time

use case 1 – use case 2 ✓

Description: Enables the patient to store baseline comparison sets and subsequent results in a way that can be tracked or graphed over time.

Benefits: Improve the user's awareness about their health evolution and trend patterns.

References: [211] [148] [68] [116] [135] [19] [34] [64] [86]

Research methods domain

At the age of sixty a person is still in good mental and physical shape and the accumulated wisdom of the years leads to superior performance in many tasks. (...)
In a world where the average age is increasing, sixty is still relatively young. We need to design with these people in mind.

Don Norman, in "The Design of Everyday Things"

Studies that are conducted in the healthcare field are considered to be a strategic research priority. Spradley gives the example of contributing to "a healthcare system that provides adequate care for all members of the society" as a way of positively impacting peoples lives [180]. From an ethnographic point of view, the research work presented in this thesis can be defined as strategic as it synchronizes human needs with scientific knowledge, with the goal of improving the quality of the citizen healthcare and senior wellbeing through the design of Integrated PHRs.

Dealing with human problems and needs involves the understanding of behavior. This type of analysis is mainly supported by qualitative research. This kind of research focuses on understanding the views and perspectives of people, covering contextual conditions within which people live, contributing with insights of emerging concepts that may explain social behavior [221]. Qualitative research has strongly supported the methods used in this thesis to gather data from the users and the several stakeholders involved on the projects of both use cases. Stakeholders included project managers, developers, physicians and nurses. Quantitative research was also applied, providing valuable findings to support the qualitative ones. Web analytics, objective questions during the interviews (e.g., applying the Likert scale) and a final User Experience Questionnaire (UEQ) [33] are examples of the main sources for quantitative results.

The research methods presented in this thesis followed a user experience (UX) design approach from user research to prototype and evaluation stages. UX ensures that when designing a solution, the expectations of the users are met accordingly to their task goals [61]. There are different interpretations, definitions and different positions when it comes to UX. Here, we assume a simple definition, which concerns to "a person's perceptions and responses that result from the use or anticipated use of a product, system or service" [198]. UX is also frequently misused when uniquely seen as usability though its domain goes much beyond the analysis of how usable a product is. Usability is just a facet among others that determine the overall experience of a digital product or service. As such, when we refer to UX we are refereeing to the following set of qualities: "useful", "usable", "desirable", "findable", "accessible", "credible" and "valuable" [199]. When defining the design strategy during the research work presented in this thesis, these qualities were minded.

Participatory methods took a primary role along the research work that was highly multidisciplinary. Both users and stakeholders were involved in the design strategy of each project, leading to the development of two Integrated PHRs proposals. These methods included participatory expert review, backcasting, semi-structured interviews, card sorting and several UX techniques such as paper prototyping for concept validation. The UX methodology model for developing a digital application or system is composed by several layers during the design process: strategy, scope, structure, skeleton and surface [61]. Each layer has corresponding elements, tools and techniques. As an example, the structure plane involves the interaction design and information architecture of the system. All together, these layers can provide the users with a meaningful user experience. The development of the prototypes followed these planes.

To conclude, UX provides flexible methods that can be adapted to the ecosystem of any product we are designing for, according to specific dynamics of a given context [195]. Along this thesis, we chose among a plethora of techniques that are available under the UX umbrella, the ones most appropriate to meet the research goals and requirements identified in each project. The methods that were applied can be found in the Research Work and Design Methodology sections, described in each use case respectively, in Part I and Part II of this dissertation.

PART I

The Portuguese Nationwide Patient Portal with an Integrated PHR

4.1. Use Case Scope

Finding strategies to design Integrated PHRs is a timely and internationally relevant problem. Several governmental programs around the world have been recently implementing reforms in the health care sector with the goal of fostering data interoperability across institutions, also building bridges with integrated PHRs that are controlled by the citizen. The European eHealth network has recommended all countries to document and evaluate the design and specifications of these new platforms to ensure that good practices are shared and lessons are learned, to diffuse the value of integrated healthcare platforms [53]. These trends were previously described in the literature review of this thesis, Section 2.1. The definition, formats and history of PHRs were described in Section 2.2.

In this scope, Nation-wide patient portals with Integrated PHRs have been emerging in recent years, to increase patient safety through online eHealth services and self-tracking tools. The goal is to empower patients and at the same time, foster team care collaboration among the providers, recording all related interactions. The main novelty of an Integrated PHR is to have a system that merges patient data recorded from the provider side with data recorded by the patient side, providing holistic views over the patient's health, which can be accessed by both parties, according to patient's permission.

In order to be populated with data from providers such as the summary care record of the patient, the system needs to be flexible enough, to connect with other medical systems, which are implemented in the healthcare institutions (for example a system that stores lab exams). In case of a Nation-wide patient portal, the PHR has a broader integration within a National Health System (NHS) network that can be extended cross-broader to other Nations. As it connects with all citizens of a country, the demands for defining a design strategy that may respond to all the requirements of a National network is highly complex. Therefore, it is necessary (1) to study the stakeholders requirements for deploying a solution that takes part of a cross-channel experience, providing the citizen with pervasive, fast and efficient eHealth services and also (2) study the diversity of current and potential users to answer the needs that emerge from different groups, which diverge in demographics and type of engagement with the portal and (3) study the full potential of having an Integrated PHR according to research directions given by the scientific community.

4.2. The Portuguese National Patient Portal

This use case presents a multi-phase design strategy to create a foundational design model for Integrated PHRs, based on the study of the Portuguese Nation-wide Patient Portal. The portal takes part of the Portuguese National Health Data Sharing platform (PDS), which has the potential of covering the total population of the country, near 10 million inhabitants. Along with the other participating nations of the European eHealth network, the platform has the ability of sharing the summary care record of the citizen across Europe. PDS provides a cross-channel healthcare experience by combining the following portals: (1) a patient portal that provides eHealth services with an Integrated PHR (with about 817,000 users in the beginning of this use study); (2) a professional portal, providing access to patient clinical data stored in the Portuguese NHS, which has been used by more than 42,000 professionals from over 565 institutions; (3) an institutional portal, providing statistics from the professional portal usage to support project and institution management; (4) an international portal, holding the summary care record of the patient for cross-border data exchange. These portals are all connected and complement each other, allowing health data from the citizen to easily flow within the NHS network, improving care delivery and health communication with the patients.

The first release of the portal occurred in 2012 when the web-based PHR started to be incorporated. A second version was released in May 2013 already with some improvements gathered by beta testers and from recommendations of this thesis. The portal is following the European Union's Data Protection Acts demand while enabling the Portuguese citizens the ownership of their data recorded by any facility of the NHS. Currently, the portal users can already access their summary care records, visualize and interact with care events from the institutions they had contact with. Any Portuguese citizen registered in the NHS can access the patient portal by introducing their unique patient identifier number. The patient portal merges EHR information such as institutional medical records that are gathered in a unique summary care record of the patient; with PHR information such as data that is collected by the patient through self-monitoring tools, representing this way, the preliminary foundations of an Integrated PHR model.

An initial study carried out by another author [22] with beta users from the first version of the portal released in July 2012, showed a strong need for a more user-friendly platform, as requested on many suggestions of participants in a survey that was conducted. An anonymous questionnaire was sent to all the users of the portal (almost 4% of Portugal's population, although the number of active users should be smaller) by February 2012 through email addresses, available for 10 days. As a result, 19,851 answers were returned corresponding to a sample of 6.61% of the total amount of registered users that were about 353,213. The sample is represented by 64.3% female and 35.7% male, similar to the ratio of the entire users of the portal. The median age was 36.5 years for female and 44 years for male. Most were married (50.9%), had children (54.4%) and went to high school.

This study revealed that the portal was in a very preliminary stage with limited functionalities and many adjustments were required. Improvements were suggested for scheduling appointments, prescription renewing, and access to the patient NHS data. Some suggestions of the participants were: "improve appointment scheduling operation"; "reduce the waiting time for an appointment to be scheduled"; "make appointment scheduling more user friendly"; "ensure that the user is notified whenever the appointment is cancelled"; "allow users to schedule specialty appointments"; "improve prescription renewal"; and "allow users to update their personal details".

When asked to score current functionalities on a 1 to 5 usefulness scale, most users scored scheduling appointments with 5 and prescription renewing with unknown/never used option. Despite not using this last functionality, users have selected greater convenience on prescription renewing, which means users had been experiencing difficulties accessing and using it, thus requiring adjustments. Regarding other feedback from the participants, they mainly relied on increasing the communication and interaction with the general physicians having suggested: "allow users online communication with their physicians in order to get health information"; "allow users to choose their general physician"; "allow users to email test results to their general physicians". To conclude, the study pointed out that the portal needed to improve the current eHealth service functionalities and enable more PHR functionalities with a special focus on patient-provider communication features.

Despite the improvements that followed, another study from this research work has revealed that the second version was yet having a limited usage. Accordingly, web analytics of the platform extracted from May 1st to May 12th of 2013, revealed that scheduling appointments was still the most popular functionality, with 189,280 views during that period. By that time, the citizen patient portal had doubled its users to about 780,000 from the previous study. From the total amount of users only approximately 18% (141,791 users) focused on self-reported data functionalities such as emergency contacts with 65,573 views, medication with 60,013 views or problems with 37,551 views during the analyzed time period. This means that the National Patient Portal was mainly being used for connecting with the EHRs electronic services of the Portuguese primary care units (e.g., scheduling appointments and medication refills) not taking advantage of PHR self-tracking tools, which were not yet very popular among the users. In fact, the platform as a new type of electronic medical record has the potential of behaving more as an integrated PHR model rather than a typical tethered Patient Portal. By having the ability to connect with more than one facility through a National network, this PHR also has the potential of exchanging data internationally. In addition, it can be populated with self-collected data, managed by the citizens who are the ones in control of their data. An integrated model has the potential of improving care quality, completeness, depth and health information accessibility [43]. Therefore, to achieve an effective integrated PHR, besides the use of eHealth services it is necessary to engage and foster the use of other health information sources more centered on the individual side such as qualitative self-monitoring tools e.g., patient diaries and assessments that report observations of daily living, educational tools and patient decision support. These features can improve care quality, completeness and add more knowledge to all the providers the patient interacts with.

In the following section of this chapter the research work of the use case will be described, presenting the methods and strategy that were followed to sustain a design model proposal for the Portuguese Nation-wide Patient Portal. The goal was to contribute with new insights and improvements combining scientific knowledge and trends with UX research methods, having as starting point the first beta version release of the portal. The proposal addresses the issues presented so far and others, highlighting key findings and actionable steps that can be extended to the design of other Nationwide integrated PHRs.

4.3. Research work

Defining a design strategy is an important stage in the design of a digital innovative product or service by determining what are the strategic needs, research direction and conceptualization of the solution. As Don Norman argues, a good concept model allows us to predict the effects of our actions as they are based on the user experience and perception [130].

The scope of the Portuguese Nation-wide Patient Portal, previously described, has framed the research work of this use case with the following questions that are related to research question Q1 of this thesis:

(Q1.1) How can we create a comprehensive structure and user experience to build a sustainable solution that may answer to the context environment and constraints of our use case study, in a way it can be extended to the design of other PHRs?

(Q1.2) Which design strategy should we follow to generate interest, credibility and trust by the current users of the portal, and attract new ones?

Having these questions in mind, the design strategy that supported the proposed model for the Integrated PHR of the Portuguese Patient Portal, was based on a UX design process and techniques with a particular focus on participatory methods, combined with previous findings and research directions from previous studies from literature. Also, the strategy that was followed, aims to demonstrate that participatory design can significantly improve health communication. Likewise, other studies have revealed that robust participatory design processes are still not widespread in the field of Health IT [128]. This research work shows that for achieving better results in the design of healthcare applications it is essential to perform cross-disciplinary research, having researchers from several domains collaborating together as a team, with complementary expertise in healthcare (e.g., physicians), HCI (e.g., designers) and computer science (e.g., IT engineers). Collaborative work in Health IT has also been defended by other authors [128] [149].

Social science was also part of the design strategy as it is concerned on creating a solution that answers to the social changing environment. This means that the design model proposal that was achieved by the end of this use case study had in account the current and desired social needs that derived from the Portuguese integrated cross-channel healthcare experience of PDS, combining complementary platforms with a Nationwide impact on the behavior of the healthcare system. Moreover, in order to provide a valuable experience, the proposal of the Integrated PHR relied on understanding its usage life cycle. By this means, designing for a set of different stages people go through when using software, considering the hurdles in between, as suggested by Porter [146].

The research work of this use case is divided into two stages, in collaboration with the SPMS team (Services of the Portuguese Ministry of Health) that was responsible for the implementation of the Nation-wide Patient Portal in Portugal. In a first stage we were concerned on answering **Q1.1** by improving the portal with a foundational design model proposal for the Integrated PHR, based on an extensive literature review, participatory design and mental models research methods. In a second stage, our concern was more focused on enhancing the experience of the users, taking the platform to a next level of engagement, answering **Q1.2**. This last stage reports the online behavior of the users and the involvement of stakeholders from the teams of project management, development, marketing and customer support, in a user-centered design process, to study the diversity of current and potential users of the portal.

During the work process, which will be detailed next, the challenge we faced as researchers was how to deal with a large organization, such as the SPMS that inevitably depends on governmental policies. Also, we were challenged to align different perspectives that were not yet consensual among the stakeholders of the Patient Portal, which we sought to mitigate by promoting a design strategy with actionable steps to improve the experience of the platform.

4.3.1 Creating a foundational model for the Patient Portal

To begin our collaboration with the Portuguese Patient portal, we conducted a participatory expert review with multiple domain experts including the SPMS team, to evaluate the status of the first released version of the platform. We wanted to involve the stakeholders to become aware of the usability problems that the users were dealing with, to be driven to improve and redesign the portal. To support the redesign of the Portal, an extensive literature review was done in collaboration with another independent researcher from the field of medical sciences (a physician who was also collaborating with the project), to gather functionalities that could support the functional analysis of the proposal. This review is described respectively, in Section 2.8, in this thesis, and also serves as a guideline to other related studies that involve the design of Integrated PHRs in any other ecosystem that may go beyond the context of a Nationwide network.

From the list of functionalities that were gathered, the functional analysis of the Integrated PHR design model was created by matching the requirements, accordingly to their relevance to the context of the Portuguese Patient Portal. Furthermore, other systems that were mentioned in several studies from the review such as Microsoft HealthVault, Hello Health or Patients Know Best, also served as an inspiration to our proposal. According to the match analysis, 11 functionalities were already implemented in the system: e.g., appointment scheduling, prescription refills and secure messaging with providers; 9 were already planned for future releases: e.g., patient access to electronic medical records from the EHRs of the Portuguese facilities, patient automated health measurements with sensor devices and telehealth appointments with physicians; 23 functionalities were not either implemented or being planned and were of major priority: e.g., patient education, healthcare support groups, observations of daily living and prevention or wellness management tools; 16 functionalities were not either implemented or being planned and were of minor priority: e.g., health risk assessments, healthcare expense tracking, pre-encounter questionnaires; referral requests.

The functional analysis that resulted from the extensive literature review was then improved in terms of clinical content by the other independent researcher, and delivered to the SPMS team. Finally, a draft of the IA that derived from the functional analysis was created and validated through a remote-closed card sorting with the goal of involving users in the early stages of the design model proposal. We were able to compare how people from different user groups (senior people, younger people, healthcare professionals and non-professionals) thought about PHR-related content and how the IA could be mapped to be meaningful to all these groups. The results influenced significantly the final IA and navigation structure of the proposal leading to an interactive prototype with responsive design.

4.3.2 Enhancing the user experience of the citizens

This stage was focused on finding the most appropriate research methods to conduct with the SPMS team, to better engage the users in the portal. According to the project stakeholders experience feedback and web analytics, the goal was to understand the characteristics and differences of both current and potential users of the platform, and group them by affinity and engagement level.

Besides statistics and web analytics, the methods were mainly focused on stakeholder participation to understand the behavior of the users while interacting with the portal, identify further user requirements, needs and limitations. Both qualitative and quantitative user research was combined for segmenting the portal user groups that by the end led to personas to inform the SPMS team who they should design for. We began with a backcasting workshop to define what strategy should be adopted to improve the portal within the PDS ecosystem. We then conducted stakeholders interviews on several domains to delve more deeply in the understanding of what have been until now the barriers and enablers of the platform adoption. Finally, through web analytics we were able to validate some insights from interviews (such as the users' most reported needs and frustrations) and add more knowledge regarding the users demographic data and online behavior. The results led to a follow-up planning agenda that would first begin with the redesign of the public area from scratch (before the login), but with valuable findings that contributed as well to the refinement of the design model proposal.

4.4. User Research

This chapter details the methods that were mentioned in the previous chapter of the research work of this use case, as well as the results that were obtained.

4.4.1. Participatory Expert Review

After the success metrics of the first online beta version of the Patient Portal have showed that the users were not taking full advantage of the integrated PHR, we decided to evaluate its status to measure content quality, user interface design and usability characteristics. In order to do so, we conducted a participatory expert review with multiple domain experts, including the SPMS team to evaluate the beta version of the Portuguese National Patient Portal (see Appendix A). We decided to conduct this method in opposition to a "typical heuristic evaluation" or an "expert review" (performed by a single or group of usability experts), as this method reduces the "evaluator effect" by combining multiple reviewers from different domains - usability experts and domain experts including the project stakeholders, to bring complementary and broader insights into the evaluation process [6]. This was the perfect match for our scenario as we combined the inputs of a physician and researcher reviewer - more focused on clinical issues; with those of a UX researcher reviewer - more focused on user interface design, interaction design and usability issues; and with the feedback of the project stakeholders - a team of developers more focused on the functional and implementation aspects.

For the analysis we combined a set of heuristics from different sources that we found most appropriate for evaluating healthcare applications. According to the existing heuristics in HCI field, we used the following set[13], which we suggest for future studies in the domain of healthcare applications:

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13 The set of the given heuristics represents the most common heuristics by Jakob Nielsen [1] (heuristics a, b, c, d, e, f); Larry Constantine [30] (heuristics g, h, i); and heuristics that are more specific to healthcare applications [15] [88] (heuristics j, k, l, m). Please note that we give brief descriptions to the heuristics. Full details can be seen on the given references.

a) Flexibility and efficiency of use: allow users to tailor frequent actions.

b) Recognition rather than recall: minimize the user's memory load by making objects, actions and options visible.

c) Consistency and standards: users should not have to wonder whether different words, situations, or actions mean the same thing.

d) Help and documentation: any such information should be easy to search, focused on the user's task.

e) Match between system and the real world: the system should speak the user's language, with words, phrases and concepts familiar to the user.

f) Help users recognize, diagnose, and recover from errors: error messages should be explained in plain language.

g) Tolerance: provide forgiveness to the user when interacting with a task.

h) Simplicity: typical, most frequent tasks are simple and straightforward.

i) Feedback: users are informed of what is happening and consequences of actions.

j) Meaningful use of color: in health applications it is particularly important to task-orient the user on health issues. Inability to differentiate colors may lead to user errors that may have consequences in patient safety.

k) Effective use of language: clinical terminology should be familiar to users and unambiguous for patient safety.

l) Educate users: engage and promote positive behaviors so users can accomplish health goals.

m) Protect the privacy of users: control who can access their healthcare information.

The Participatory Expert Review was conducted through a remote session with the reviewers from the several domains who were asked to interact with the system according to pre-defined given tasks such as "add medication", "add an emergency contact", "manage information sharing", "measure weight". Initially the facilitator of the session (the UX researcher) presented a brief context of the method and explained the goals of the evaluation, the meaning of the given heuristics and what were the severity ratings for classifying usability problems. It was also explained what was considered to be a usability problem. The session invited participants to navigate in the interface according to the tasks and identify usability problems. The problems were identified in accordance with the provided heuristics, naming which of them were being affected in each task. Upon the identification of a problem, its severity level was attributed only after the consent of the whole group. By the end, participants were asked to give suggestions for improving each problem or raised questions. We also extended the evaluation to the new User Interface (UI) proposals created by the SPMS development team that were already being planned for the next version release.

As a result, 92 usability problems were identified and rated in our report according to Jakob Nielsen's severity ratings scale [169]. At this stage, we explained with more detail, what we had found and why the portal should be redesigned from scratch. The beta version of the Portuguese Patient Portal had major problems with readability (e.g., the size of the font was too small); the navigation options were not clear; the main navigation menu offered poor contrast; the styles of the titles were confusing; there was a lack of a clear visual hierarchy of the UI components and colors and in a general way, they were not used effectively and did not help to prioritize the information. The information architecture (IA) also revealed problems, misplacing levels of importance (e.g., the clinical summary appears as secondary menu instead of primary - being an important feature to the user, hard to find; the medication orders appeared in a different location from historical recipes). Content was not presented naturally and both terminology and language were not clear and straightforward enough to the participants that were novel to the portal, mainly because the terms used technical language, with an overweight use of abbreviations (related to the healthcare system conventions not interpreted by lay people).

To conclude, the first release of the application involved technical, clinical, functional, structural, interaction and visual problems. This was due to a lack of design strategy in the beginning of the portal development, which consequently affected the user experience. As major contributions, our key recommendations suggested that it was urgent to rethink the structure of the portal in what concerns to the information architecture; navigation and interaction design; content strategy, terminology, used language and visual design hierarchy. We appealed to the team that a consistent layout should be created, using plain and unambiguous language. The most specific clinical terminology should be patient-friendly and relevant to the users (e.g., acronyms or abbreviations should be avoided). The UI should be self-sufficient, focused on the user tasks and contextual help should not be too extensive.

As future directions, we also suggested that efficient search mechanisms should also be created; and the system should evolve to be able to respond to the user profiling. As an example, a person with diabetes should receive patient education and personal decision support according to her specific problem needs.

4.4.2. Users Mental Models

People construct mental models according to their beliefs, experience and personal knowledge, playing an important role in intentionality and human reasoning [179] [155]. Indi Young in “Mental Models: Aligning Strategy with Human Behavior” [222], gives us the following definition: “Mental models gives you a deep understanding of people’s motivations and thought-processes, along with the emotional and philosophical landscape in which they are operating. A mental model consists of several sections, with groups within each section. Mental models are simply affinity diagrams of behaviors made from ethnographic data gathered from audience representatives”. The author defends that mental models provide a user-centered design approach, generate features, provide vocabulary for labels, give an high-level information architecture and most of all, align the content with the mind set of the expectations of the users. To design for the Integrated PHR usage life cycle, this research found mental models, a determinant qualitative method to work with.

In order to address the challenges of designing a Nation-wide Integrated PHR, we conducted individual and closed card sorting, to detail the mental models of the users to inform the creation of a meaningful information architecture (IA), in our design model proposal. Card sorting is an evaluative straightforward method that helped us understand the people we are designing for. We used it to check if our IA decisions made sense to the users; to learn and compare how people from different user groups thought about the content; how content could be grouped; to explore whether there was one main classification scheme for the content or whether there were other possibilities; and finally to involve and justify our IA to the project stakeholders.

The audience participants that took part of this study are divided between senior and younger people. We found important to understand the differences between these two groups, as the Integrated PHR foundational design model that represents the main contribution of this use case, serves as a work basis for the second use case that follows this research work - The Portuguese Senior Nationwide Telehealth Program. In addition, the preliminary study conducted with the platform users by another author [22], also revealed a strong gap on the platform usage by older people. Moreover, we also wanted to understand the differences between how healthcare professionals and lay people think and organize PHR-related content. Past research revealed the need to detail mental models of lay individuals and providers in order to achieve comprehensive system information architectures that reflect the patient's roles and needs [79]. This need inspired the goal of also involving healthcare professionals in the study, mainly because they need to access the patient data reported by the citizen in the Patient Portal, through the Professional portal from the PDS platform.

We chose to run remote and individual closed card sorting sessions with the different audience groups. To gather a larger number of responses, we found more appropriate to coordinate individuals rather than teams through a remote online software tool called OptimalSort[14] (see Appendix C). Despite not using the "think aloud" method during the activity, we found that involving more people was a clear advantage in this case: the Integrated PHR was being used at the time by a large number and diversity of people, having the potential of including any Portuguese citizen registered in the NHS. Nevertheless, one of the sessions conducted with the senior user group, allowed us to combine face-to-face activity with software-based sorting, enriching our outcomes.

We opted for a closed card sorting because of the complexity of health content, inherent to the nature of healthcare applications. This method allowed us to guide our participants in organizing the cards within a main structure, rather than creating all content levels from scratch. This assured more control over the outcomes of the sessions.

The Information Architecture labeling and grouping, were a result of the previous extensive literature review and functionality gathering process, described in section 2.8 of this dissertation. The first two navigation levels of the system information architecture (IA) were evaluated. Descriptions were added to the cards so that the participants could understand more complex content like clinical terminology. The first level of cards from the given IA to the participants with the respective descriptions were as follows:

14 http://www.optimalworkshop.com/optimalsort.htm

> **Personal Data:** My personal and administrative data.

> **Healthcare System:** Interactions with the healthcare professionals and facilities of the NHS.

> **My Health:** Current and past history about my health.

> **Health Management:** Tools that help me to manage my healthcare in my daily life.

> **Health Education:** Learn and know more about treatments, diagnosis and health related topics.

> **Information Sharing:** Share my data and my records with others (healthcare professionals or family).

The sample of the participants in the study reached a total of 73 people, divided into two user groups, the senior user group and the younger user group, represented in Table 1.

Younger Group	Senior Group
Total of 62 participants	Total of 11 participants
Mean age = 33 years old	Mean age = 64 years old
33 Female / 28 Male	10 Female / 1 Male
23 healthcare providers	3 healthcare providers
35 people had already heard about the Portal	3 people had already heard about the Portal
9 had already used it	None had ever used it
Environment: online through social network and email	Environment: presencial in a senior university
Time taken in optimal sort: 10.9 min average	Time taken in optimal sort: 35.2 min average
Duration: ran remotely during 4 days	Duration: 2 days sessions with moderator help

Table 1: Participants demographics from the study divided into younger and senior user groups. The table also includes the environment where the study was run, task time performance and timeframe duration.

Sessions were ran differently with both groups. While the senior user group was conducted in two moderated sessions held in a Portuguese senior university (Universidade São João de Deus, Lisboa) with 11 participants, the younger user group corresponded to a broader audience, with whom remote sessions were conducted during 4 days, reaching 62 participants. In this last group, invitations were sent to the general public through social networks, as well as to beta testers of the PHR project through their email. Healthcare providers (26 participants) took part in each group, randomly: 3 from the senior user group and the other 23 from the younger user group.

4.4.2.1. Restructure of the Information Architecture

The results influenced significantly the final structure of the IA. Both first and second navigation levels suffered changes in the given category labels and content grouping. The first level categories that worked best for both user groups were "Personal information", "My Health" and "Health Education".

The categories that presented more conflicts and doubts for both user groups were "Healthcare Management" and "Healthcare System". Many cards from "Healthcare System" were considered ambiguous and suggested to other categories such as "My Health" or "Healthcare Management". When people did not know where to place content, they placed in the category of "My Health".

We did not find significant differences between the mental models of senior and younger people, as both groups highlighted the same conflict cards (see Figure 10), except regarding privacy control and system operational features content (e.g., manage system accesses in the PHR). This was reflected by the doubts that senior people had with the "Information sharing" category (which worked well for younger people and not for the seniors). Probably this is due to the fact that senior people are less used to this type of features when compared to younger people, who tend to have more software experience. Moreover, "Family doctor" was mostly placed by seniors in "Information Sharing" while younger people chose the "Healthcare System". This may be related to the fact that possibly seniors have a stronger relationship with their family doctor, leading them to choose a placement that reinforces their wish of sharing their information with the providers.

Healthcare professionals were the ones who showed more agreement with the initial IA, probably because they are more aware of how the healthcare services work and are more comfortable with clinical content, in comparison with lay people. This applies to all healthcare professionals regardless the group to where they belonged (seniors or younger people).

Disagreements between these healthcare providers and lay people, showed us that functionalities that were related to the interaction with the "Healthcare System" are perceived by the first group as a way of sharing information with their patients, moving the cards to the "Information Sharing" category, while in lay people is seen as a way of managing their health, moving the cards mainly to the "Health Management" category but also to the "Personal data".

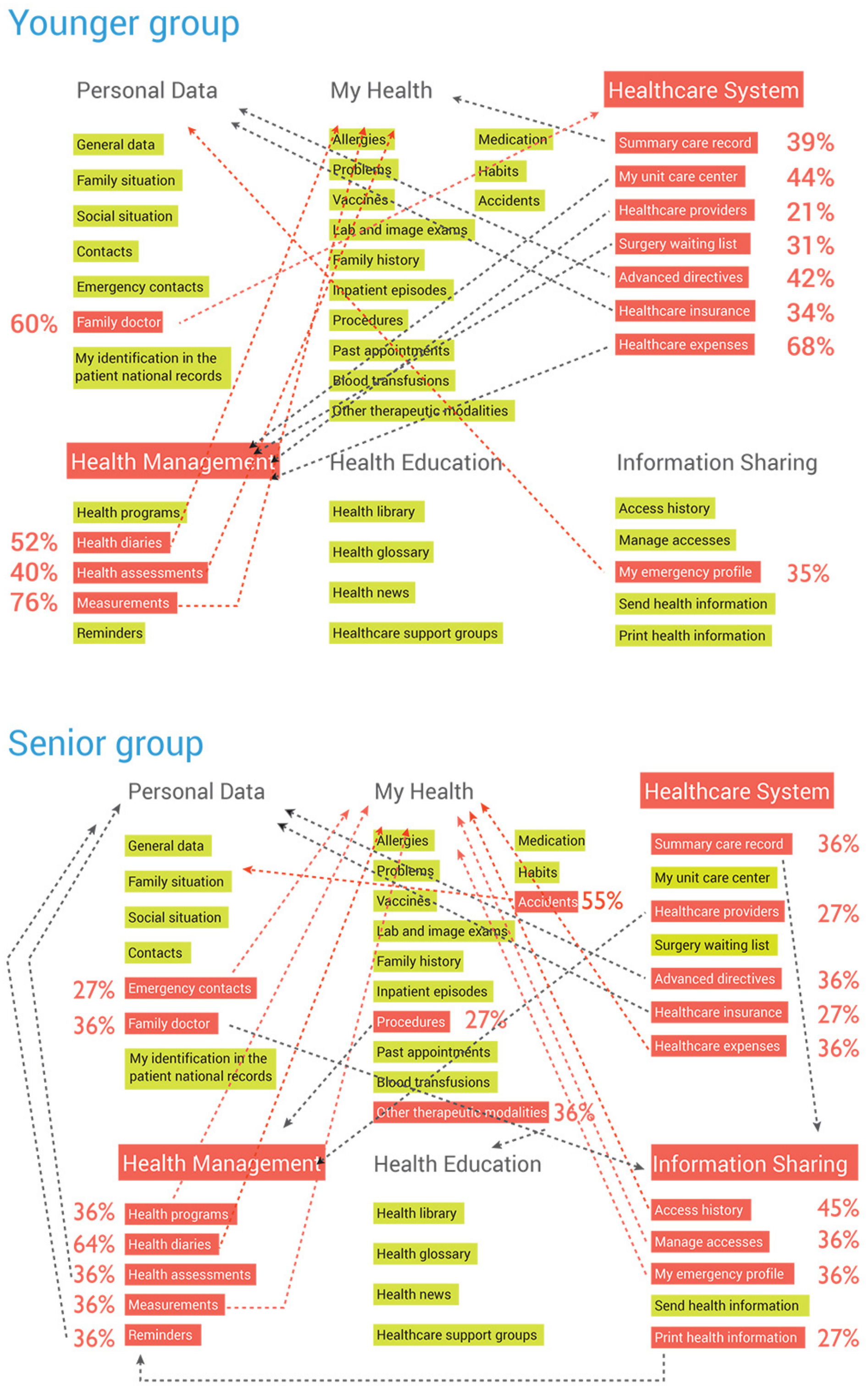

Figure 10: Overview of the highlighted conflict cards in the IA that show divergent values above 20% for both user groups.

Figure 11: Final Information Architecture.

We replaced "Healthcare System" for "Healthcare Providers" and moved cards to the most suggested places (see Figure 11). As "Healthcare Management" was also considered to be an ambiguous name, we decided to change it to "Healthcare Monitoring" reinforcing the monitoring of qualitative and quantitative health measurements. We also considered the suggestions and comments of the participants in the IA restructure (there was the opportunity to change the default names in a suggestion field during the organization of the cards). One example was to divide "My Health" into two other sub-levels - "Health History" and "Basic Information", because according to one of the participants this group was too overwhelming, explaining: "My Health ends up receiving excessive content, harming the navigation experience". The information architecture specification can be found in Appendix J.2.

4.4.3. Backcasting

Backcasting is a strategic planning method based on stakeholder involvement in the creation of sustainable futures, combining participatory design and analytical activities [154]. We found this method to be a good starting point in stage two of this use case, which was centered in enhancing the experience of the diversity of users of the Nationwide Patient Portal and also in increasing its awareness by attracting new users. Firstly, the method allows the implementation team to think about possible scenarios and strategies to improve the portal engagement and as a consequence, be persuaded to better understand their users. Secondly, the method avoids the effect of "confirmation bias" which in this case may easily occur, because we were working with a pre-existing solution (the second release of the portal).

Figure 12: Backcasting workshop setting at SPMS facilities.

The backcasting consisted on a workshop conducted at SPMS facilities (see Figure 12) where a team of stakeholders was recruited with the following participants: the project manager, the product leader, two developers and the marketing manager. The workshop promoted a brainstorming approach, leading the team towards what were the project milestones that could benefit the NHS. The session began by introducing the goal and advantages of the method and with an introductory question to kick-off the activity:

How far in the future will we start from?

To answer the question they wanted the public portal to achieve a maturity state between 6 months to 1 year from the present. In order to attract new users, the group was more focused at this stage, in defining the communication strategy of the portal public area (before the login) - what would make users sign in?

The following questions structured the activity into several moments: participants were asked (1) to baseline the current state of the portal (with its limitations and problems); (2) to define the main possible future states; (3) to work backwards and identify indicators; (4) to assess risks, opportunities and actions.

We worked on a board with multiple stick notes of different colors to map the desired futures (large pink sticks) through a visual language: yellow for indicators, pink (small sticks) for risks, green for opportunities and orange for actions (see Figure 13).

Figure 13: Backcasting mapping result.

By the end of the workshop we had mapped out the desirable futures for a successful portal, which led to a follow-up agenda and ideas for implementation. We have the following findings from backcasting:

- **Unique cross-channel experience:** Integrate all portals of the PDS - National Health Data Sharing Platform (patient, professional, institutional and international portals) in a unique cross-channel experience. This is an opportunity to model the different portals into a consistent and uniform platform behavior and to enhance credibility by giving users the perception of an integrated system. Integrated views in the user interface can be created so that users can easily switch between portals according to their role (provider or patient), also combining the overall institutional and international perspectives. As main risk, people can get confused with several view modes.

- **Meaningful content:** simplify the current portal content and develop new content for foreigners living in the country. The goal is to achieve a natural information architecture that can be further validated by usability testing. As actions, it is necessary to identify which content is mandatory; create new one for foreigners who need to receive care in the country; rethink the structure and applied terminology. As risks, it is necessary to deal with the complexity of the current portal information - How can we simplify it?; and with the transition from the current version to the new one (in an initial stage this can increase customer support).

> **User engagement:** promote the awareness of users about the benefits of the Nationwide patient portal with an integrated PHR. Users should understand the advantages of using the portal and PHR features to manage their health, the benefits of assessing their summary medical record and share their data with the NHS professionals of the platform. We can measure first time engagement with the increase of new users registration. We can explore multimedia content (promotional video, rotating images and appealing messages); give visibility to login; create call-to-actions for registration; give users a simple landing page with a brief description about the benefits of the portal and a summary of the PHR functionalities. With these actions we have the opportunity to maintain regular users and attract new ones.

> **Inclusive portal:** create an accessible portal in any device with W3C validation, including multi-language for foreigners. The goal is to have a universal portal, accessible by everyone, in any device, who needs care from the NHS services. In a first stage, we need to create specific content for foreigners by explaining the overall experience of the NHS; follow the W3C accessibility standards; have responsive design to access the portal in any device. This is an opportunity to optimize healthcare delivery in the NHS and be an example for other government portals in the healthcare sector.

4.4.4. Stakeholders Interviews

Interviews from different domains that followed backcasting, brought deeper insights of the portal user experience as participants were focused on how to engage current users and attract new ones. The structure of the interviews can be found in Appendix B. In order to gather relevant project-related insights, regarding what could be improved, what were the project hurdles and needs from various points of view, we interviewed eight stakeholders with several roles in the project: the project manager, the product team leader, one developer, one person from customer support, one business intelligence analyst, the marketing and communication responsible and a consultant physician. We grouped the answers according a set of topics as follow: product strategy (answers from four participants), marketing (answers from two participants), service and content design (answers from six participants), user experience (answers from six participants), product development (answers from four participants), customer support (answers from two participants). A summary for all answers within each group is provided in this section.

4.4.4.1 Product Strategy

The nation-wide patient portal can benefit the NHS by increasing the security of care delivery and by sharing patient data with healthcare professionals within the platform ecosystem. This is an exclusive service as there is no other system that enables the access to patient data throughout the country. According to the product team leader:

> *"The portal empowers citizens to access their patient summary record and health episodes in a timeline. It also enables citizens to easily access electronic health services in a confortable way, without the trouble of visiting facilities."*

The main functionalities are schedule appointments (by now 80% of the portal usage); prescription renewal; request for health tax exemption; access the surgery waiting list; access the patient summary; access the children's health record eBook and view the NHS timeline events. By the time this activity was ran, the team was working to release the "vital will" functionality and in the development of telemedicine services, hoping that in the future, physicians and patients can have online appointments by videoconference. There are several aspects that can be improved for a better integration of the patient portal with the PDS. The project manager asserted:

> *"Many citizens are not aware yet of the potential of the portal because they do not see the overall experience of the PDS."*

We need to convey a message of trust to the citizen to start using the portal and find strategies to persuade users to record their health data. Another related concern is data privacy. The portal must show, in a clear way, the efficacy of the system security to its users. This issue has been actively discussed among the team. An example, for building trust, could be to notify the user, each time a healthcare professional consults his/her profile.

4.4.4.1 Marketing

The patient portal can be promoted through TV, radio, social networking and campaigns run in pharmacies, hospitals (both public and private) and primary care centers. A campaign named "Click for you health" where flyers were distributed to promote the portal in healthcare institutions had already been conducted. It got the attention of healthcare professionals in hospitals who were willing to promote the portal among their patients. Another campaign called "Word-of-mouth", that aims to identify among our portal ambassadors (portal users that where selected to promote the portal) the people with an appropriate profile to spread the word of the existing portal services among their friends, was undergoing by the time of this activity.

4.4.4.2 Service and content design

The contents in the public component of the portal (website before the login) should be reorganized and simplified. It should be clear to first-time users the services and benefits the portal offers. In order to engage users with the PHR functionalities, it is necessary to build trust in the patient-provider relationship enabled by the platform. As pointed by the marketing and communication responsible:

> *"It needs to be clear that self-collected data from the patients can help healthcare providers to follow their health condition through time and also help them make better diagnosis."*

The portal could also benefit from more features, such as patient exams. This access, along with intelligent recommendations could help decrease patient's anxiety during treatments, having also a positive impact on their recovery. Health questionnaires could also be enabled to prevent risk situations in the patients. Updated news can also offer credibility to the portal and inform users about new treatments or NHS events. All content should be clear and use plain language.

4.4.4.3 User experience

The portal experience before the login has the importance of encouraging users to register but that is only possible if they see value in doing so. People get lost in the public area of the portal before they login. This harms the experience because people leave before they even try it (some of them do not even find the place to login). To solve this problem the information architecture has to be improved and a user-task-oriented navigation has to be implemented. The user experience could also be improved by integrating in the portal community health online forums. As suggested by the business intelligence analyst:

> *"Health topic areas with questions and answers could help engaging patients and providers. Also, the portal could enable "health information cards" that would share the experiences of the patients including videos and images.*

In summary, several strategies can be followed to attract new users: facilitate the access to login and registration. Mainly, avoid the login with the citizen identification card reader by finding other ways of offering secure access to sensitive data (see Appendix A.3. for the UI that was displayed to the users when they accessing their summary of care, during the portal's sign in or login); have calls-to-action for registration with motivating messages; have a more appealing visual design of the portal; enable more attractive features to users, e.g., telemedicine; create a more inclusive portal by going beyond the typical usage of managing health problems, engaging new target users like young people or sport lovers who can use the portal for managing their well-being performance. The developer suggested:

> *"A future component for wellbeing could be integrating the portal with third party applications (e.g., RunKeeper), to engage users on having a regular access through a gamification and reward strategy, also providing meaningful recommendations."*

After the above comments, we now show the desirable reactions that the team would like to accomplish in the user experience of the portal according to a set of 16 cards from Microsoft Reaction Cards [16] that we provided. The three major reactions were: accessible (17%), intuitive (14%) and secure (14%). Followed by engaging (11%), motivating (11%), trustworthy (9%), appealing (9%), useful (6%), valuable (3%), meaningful (3%) and efficient (3%).

4.4.4.4 Product development

In what concerns to the public area of the portal, success also depends on the technology that is behind the system that integrates with legacy systems. Solving the technical problems of the previous architecture, the electronic services and global functioning of the portal could then be improved. The new layout should contemplate responsive design to create an accessible portal in any device. The login with the citizen identification card was at that time a problem to be solved. There is a will to improve accessibility by conforming to the W3C guidelines.

4.4.4.5 Customer support

The average number of calls from users is 40 calls per day. The user groups that mostly contact customer support are people between 20's and 30's (some of them responsible for household family members and looking after older parents) and over 60 years old. The most common contact scenarios are: older people, who usually need help for scheduling appointments; younger people who need help for requesting health tax exemption. The main reported usability problems are concerned with login and registration processes. In many reports, users wish to access their summary care record and clinical data without the citizen identification card reader (see Appendix A.3). Some users ask if their medical exams are accessible outside their clinical episodes. The person from customer support explained:

> *"As reported, users expect their data to be accessed only by healthcare professionals during the appointments or other health episodes with the NHS. Most users are afraid that people can access their clinical data without a strong reason for doing so."*

Other user reports are concerned with PHR limited functionality behavior. As an example, people have reported that they cannot upload documents, which they consider to be important (due to upload capacity limits).

4.4.5. Web analytics

Web analytics have confirmed usability problems that derived from the previous interviews, which have been the cause for the low time spent using the portal.

By the beginning of this study, the nation-wide patient portal had about 817,000 registered users excluding the associated household family members that access the portal with an average of 5,000 visits per day. If we include the household family members, the total amount was 990,000 users. This number represents approximately 10% of the Portuguese National population.

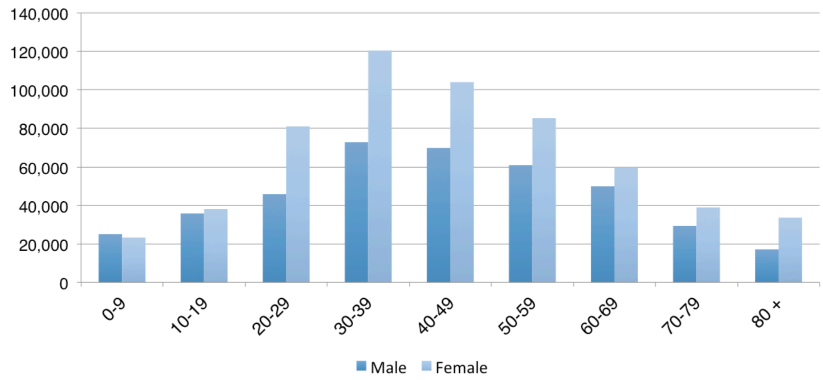

Figure 14: Demographic distribution of the registered users by age and gender with associated household family members.

The most typical users are women between 30 and 39 years old. Women surpass man in all demographic age groups except between 0 and 9 years old (see Figure 14). During the year 2014 (until November), the main used functionality was the request of scheduling appointments with approximately 360,000 requests; the most used PHR functionality has been habits with 275,000 records, followed by medication with 20,000 and problems with 6,550.

Web analytics extracted from the portal within a six-month period (from 1st of March to 31st of August of 2014) have reported 781,778 visits from its users. From this amount, 22,7% lasted less than 10 seconds and approximately one third of the visits (36,4%) stayed no longer than one minute. This represents a large number of users that access the portal and do not stay enough time to perform any task. The majority of abandoned pages (approximately 42%) are at the moment of login and registration.

These indicators, stand along with the previously reported feedback from backcasting and stakeholders interviews that explain the current complex mechanism behind these tasks: the access to clinical data is only possible through a citizen identification card reader that often fails (feedback from user experience); technical problems due to dependencies from older and third parties technology (feedback from product development); or how hard it is to find the place for login in the navigation (feedback from customer support). In second place comes the request for health tax exemption functionality, followed by homepage and the page for scheduling appointments (which also represent the most wanted features). The largest visit durations are divided into two groups: 25,2% spends between 3 and 10 minutes and 23.5% more than 10 minutes. Together, these values correspond to approximately half of the visits, which represent significant user engagement with the portal. Furthermore, within the set timeframe, the portal reports 50,15% of new visitors and 49,85% of returning visitors. Both groups consult an average of approximately 7 pages per visit. This means that despite the reported low spent time in the portal (36,4%) the portal has been attracting a large amount of new users.

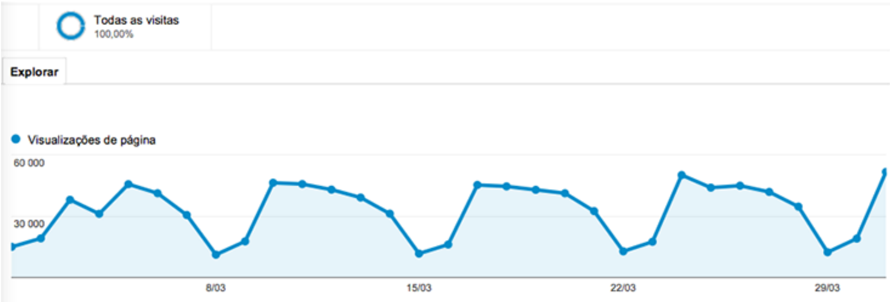

Figure 15: Page visualizations of the Portal demonstrate higher accesses on Sundays, decreasing during the week until Friday.

According to the portal user traffic analysis, it is interesting to see that the larger number of accesses are performed on Sundays (see Figure 15), and decrease during the week until Friday. This shows a behavior pattern of the majority of the users who seem to choose Sunday for managing their health affairs. Furthermore, people who most access the portal are located in or near the largest cities in the country of Lisbon and Porto as we can see in Figure 16.

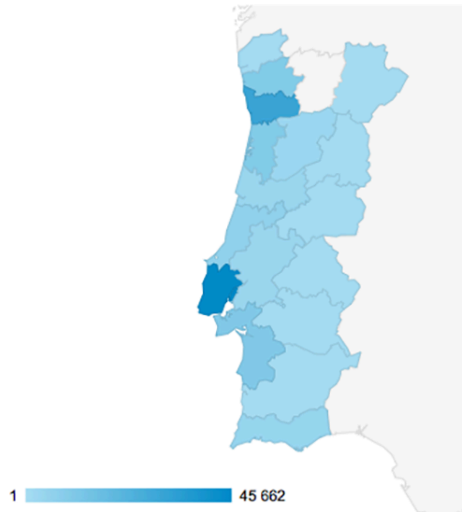

Figure 16: Users distribution across Portugal are located in or near the largest cities of Lisbon and Porto.

It is also meaningful to understand how people find the portal and which terms they use for searching. Traffic analytics shows that around 60% of the visits are referred from other government health related portals and only 20% are from search engines. This means that the patient portal has still to gain visibility and more impact among national inhabitants. In what concerns search terms, people often search for "patient portal" or "health portal". They also search for the most used functionalities, i.e., "scheduling appointments in the NHS", "surgery waiting list", "request for health tax exemption". Other people may find the portal while searching for health related topics, e.g., "headache".

4.4.6. User Groups and personas

By combining web analytics with findings from the stakeholders' interviews, we were able to identify the several attributes of the users such as primary goals, roles, demographics, experience and group them by affinity (as examples of the personas, see Figure 18 and Figure 19 in the end of this section). According to the methods results, users can have mixed roles and belong to more than one group. We also created personas as representative audiences for each group.

Figure 17: Distribution of personas by the stakeholders during a workshop conducted with the SPMS team.

Each persona had personal information and a detailed profile, use case scenario, user goals and the specification of a user experience task, crossed with the goals of stakeholders (see examples in Figure 18 and 19 at the end of this section). A last workshop conducted with stakeholders of SPMS, allowed us to put the team "in the users' shoes". Each participant had to "fit" the persona and present it to the rest of the group through storytelling (see Figure 17).

Each user group details a description, the main goal and the potential of the engagement level that the users have with the platform, according to the usage lifecycle and user needs. The engagement levels were defined according to Porter in "Designing for the Social Web" [146] as: unaware, interested, first-time use, regular use, and passionate use. All the personas can be found in Appendix J.4.

By the end, the team understood the challenges and condition-specific requirements of the variety of user groups that the Nationwide portal should answer for to provide a complete experience to the users. User groups described from 1 to 6 are current users, and from 7 to 9 are potential ones:

1. **General public:** People from a wide demographic sample who find the portal when searching for information related to health topics or to the NHS services: e.g., search by a disease; look for health facilities. Main goal: health information. Engagement level: interested or first-time use.

2. **Active adults:** People between 20 and 65 years old, mainly women between 30 and 40 (the largest user group registered in the portal). Look for quick online healthcare services to articulate health appointments with their busy daily work lives. Main goal: eHealth services. Engagement level: regular use.

3. **People with long-term conditions:** People who have long-term health conditions such as Diabetes. Access the portal with the particular interest of renewing their usual medication or to monitor their health problem. Main goal: eHealth services and self-tracking tools. Engagement level: regular or passionate use.

4. **Householders:** Parents caring for their children (usually mothers). Look for a particular feature: the children's health record eBook to register the growth of the child, over time (the eBook replaced completely the paper version). They receive portal notifications to follow up the NHS program for children. Main goal: eHealth services and self-tracking tools. Engagement level: regular or passionate use.

5. **Senior people:** People over 65 years old usually retired, who may suffer from multiple health problems. Access the portal with the

particular interest of scheduling appointments, access lab tests or renewing medication. Have the potential to become interested in monitoring their integrated health through self-tracking tools. Due to a usual low digital literacy level, they need system support such as a help area. They are the most frequent group to call customer support. Main goal: eHealth services and self-tracking tools. Engagement level: regular or passionate use.

6. **Children and grandchildren:** People above 20 years or older who help their parents and grandparents to manage their health. Use the portal for scheduling appointments, renewing medication or other services. Main goal: eHealth services. Engagement level: regular or passionate use.
7. **Underrepresented population:** People with very low or no digital literacy such as isolated elderly without access to the Web or people with financial needs. Possible scenarios are elderly people who may need to see their position in a surgery waiting list or unemployed people who need to request health tax exemption at the portal (frequent scenario). These groups usually go to primary care centers, to ask for help. The portal has to support users to perform the request or any other action, in someone else's name. Main goal: eHealth services. Engagement level: unaware.
8. **Foreigners:** People from abroad living in the country. The portal should welcome these people with a specific area that explains the general functioning of the NHS, offering multi-language support. Main goal: eHealth services. Engagement level: unaware or first-time use.
9. **Wellness group:** Any person who is interested in wellness activities, health prevention and concerned on having a healthy life. The portal should engage these users through PHR features such as care plans for diet or integrating with third party apps that track sport and wellness events, e.g., connect with Runkeeper of Fitbit devices. Main goal: self-tracking tools. Engagement level: regular or passionate use.

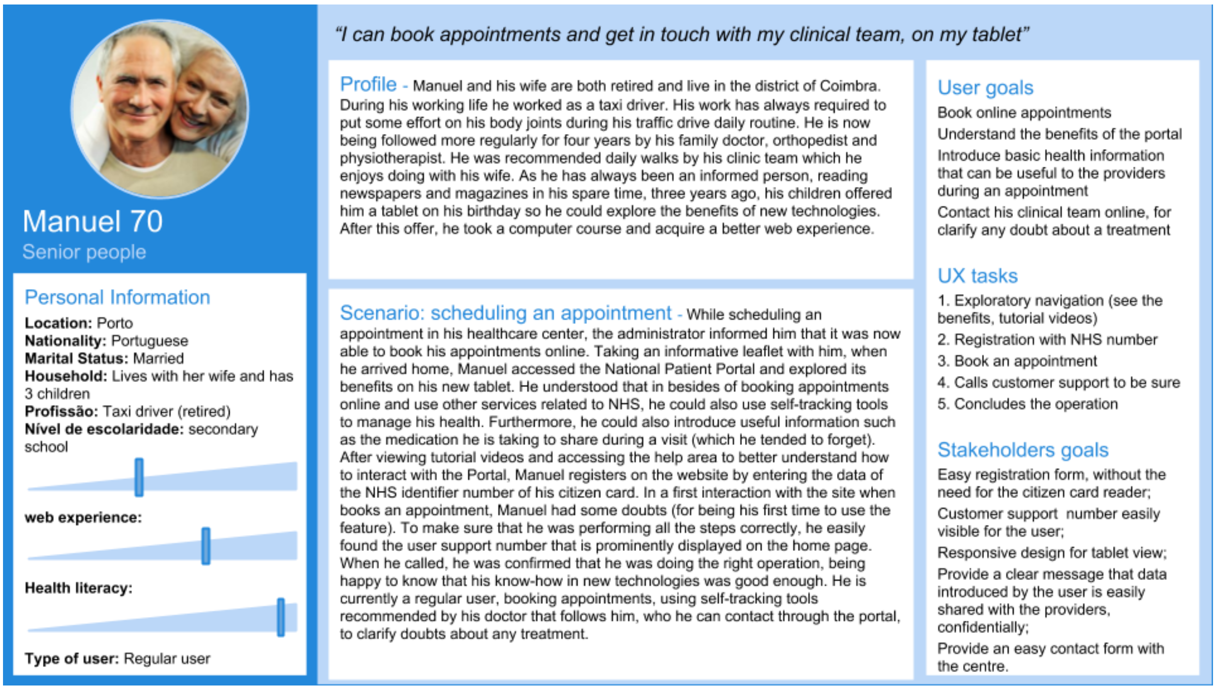

Figure 18: Persona for the senior people user group.

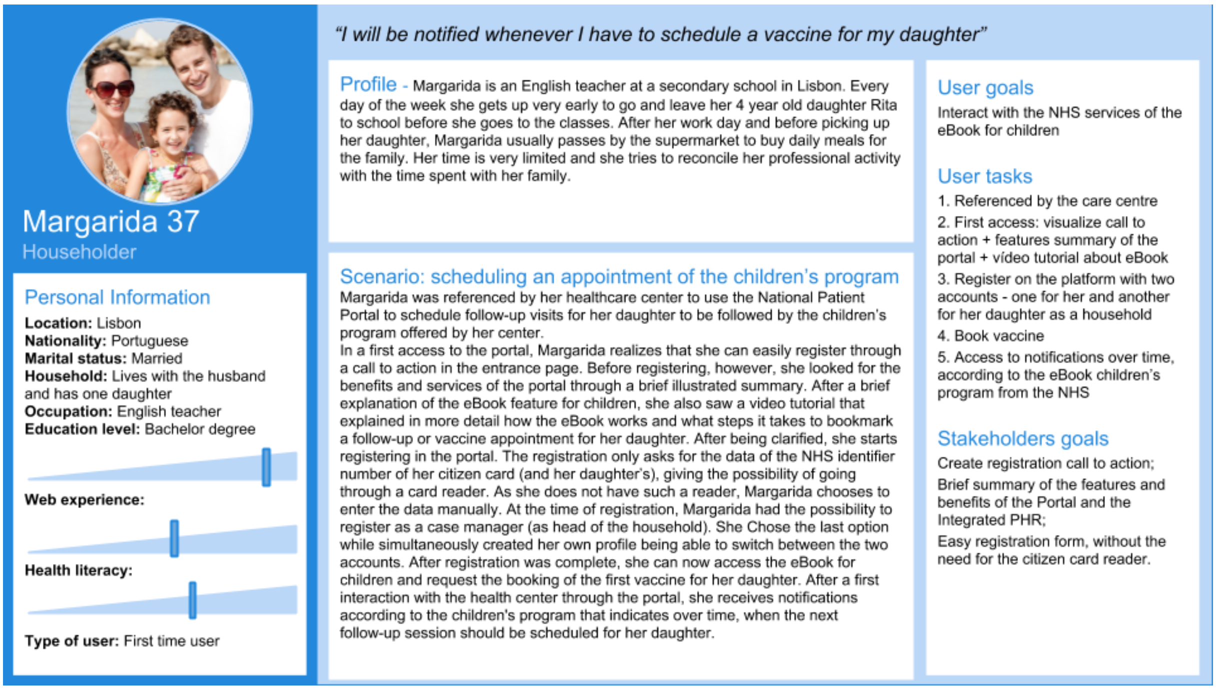

Figure 19: Persona for the householders user group.

4.5. Design Model Proposal

The design model proposal for the Integrated PHR, inspired in the Portuguese Nationwide Patient Portal was sustained on a functional analysis that derived from the user research findings of this use case and based on the extensive literature review. All functionalities (total of 55) had descriptions justified by what was found in literature, system requirements, including UI components needs and the corresponding positioning in the Information Architecture (IA). The functional anaylsis specifications can be found in Appendix J.1. The functionalities that were selected from the review are checked in the Integrated PHR features collection, Section 2.8 in this thesis.

This chapter contemplates the application structure and the user interface design (UI). The proposal of the Integrated PHR was designed with wireframing[15] detailing all the UI mockups of the application. The complete set of the mockups can be found in Appendix J.3. Only at the end, the visual design was applied to a set of pages that could inform the development of the prototype as a template. The visual design can be found in Appendix E. The website public area of the portal was also designed later, in a more agile way, by creating a set of mockups that included the visual design as a template.

All the deliverables were shared with the management and development team of SPMS, as a result of the collaborative work in this research. The material also included a video tutorial about how to implement the design of the Patient Portal proposal according to the set of deliverables that were accomplished. This video tutorial can be found in Appendix J.5.

15 Balsamiq software was used for this work - https://balsamiq.com/

4.5.1. Application information structure

This section represents the proposal for the main structure for the application of the Portuguese Nationwide Patient Portal (see Figure 20) in a diagram with two navigation levels that also includes the public area before the login and its entry mechanisms.

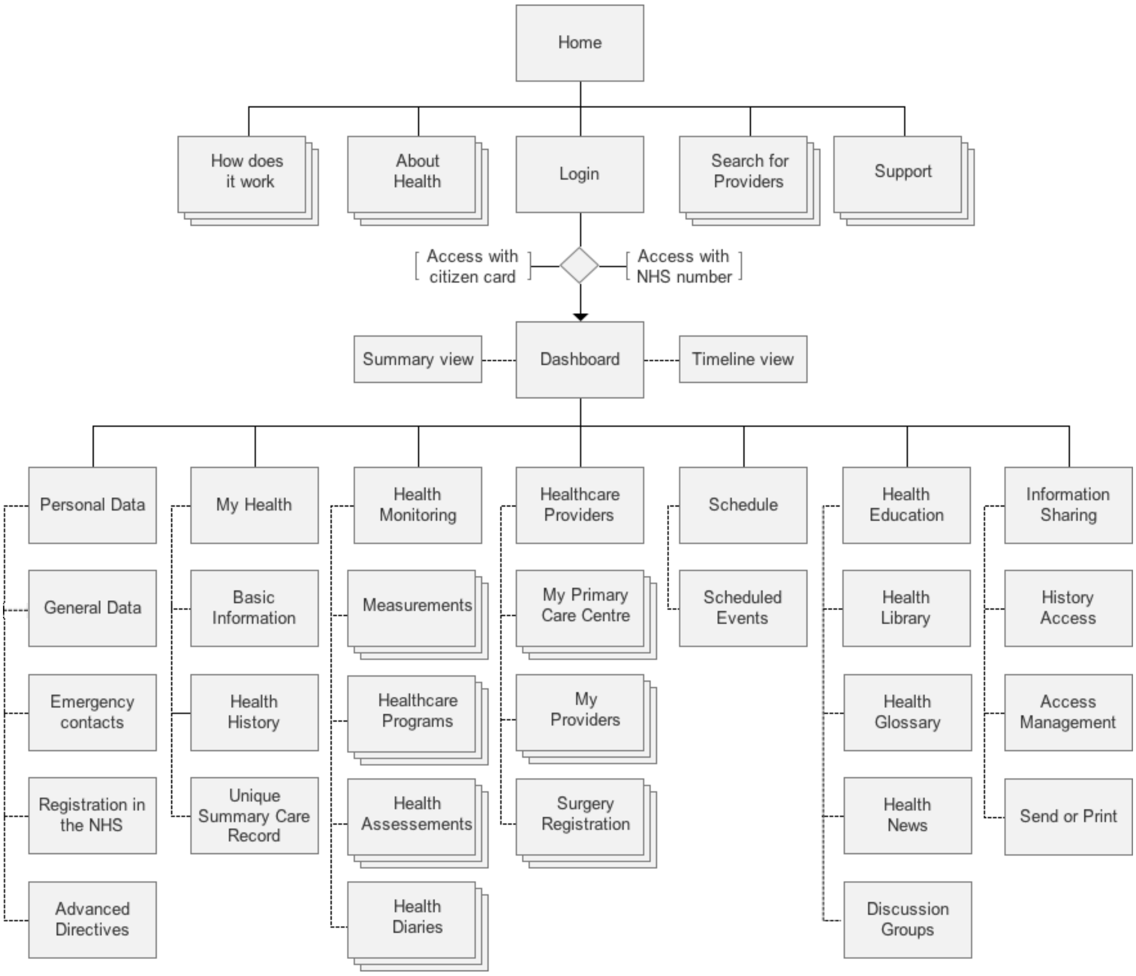

Figure 20: Proposal for the application information structure of the Portuguese National Patient Portal.

4.5.2. User Interface Design

The UI describes all the areas that compound the proposal of the Integrated PHR and a brief description of the public area (before the login). The interaction design contemplated storyboarding, representing a set of user task scenarios. The main tasks included “adding an emergency contact”; “add an allergy”; “add a medication”; “add a health problem”; “add weight and BMI measurement”; “schedule an appointment in the primary care center of the NHS"; "share profile with someone trusted by the user".

Several UI techniques were applied to stimulate the users to perform their tasks such as components of "call to action" or "edit in place"; wizards to guide the users through the process of entering health data (e.g., add medication); contextual help with complementary media (e.g., videos about health prevention and wellness recommendations); personalized header in the UI to make users feel they are in their own space (e.g., showing their picture and a shortcut to a specific module that monitors a health condition like pregnancy); quick buttons to easily perform more common tasks; easily switch between users (e.g., a mother who manages her son's information and can access both profiles).

During the design, one concern was to make an inclusive UI for senior people, thinking about usability constraints they face. One strategy that was followed was to display a clear navigation making interaction components available to the user as much as possible, avoiding a deep navigation. The look and feel of the proposal was inspired on the existing official branding of the Portuguese National Patient Portal, specifically on its second release. However, changes were made to UI visual design in what concerns to colors, typography, iconography and information visualisation techniques such as sparklines, very effective to rapidly compare different measurements in medical records [178]. Visual hierarchy used differentiated buttons (primary vs. secondary buttons), titles and content labels. Iconography was used only when necessary. The dashboard was designed to be appealing and to integrate a summary view of the user basic health data and their recent activity with the portal. The goal was to encourage first-time users to start interacting with the features of the PHR as well as to engage regular users to keep their data up to date.

4.5.2.1. Dashboard and Header

The information available at the dashboard, is divided into two views: "Summary view" view and "Timeline view". The "summary view" (see Figure 21) displays the records of the user most recent tasks in the PHR, allowing an overall visualisation about their status with shortcuts to their respective areas. It also included quick buttons for the most used eHealth features of the Patient Portal (that interact directly with the NHS), i.e., "schedule an appointment", "request medication renewal" and "see surgery waiting list status". The tasks report several events from the system such as upcoming clinical appointments, privacy control interactions (presenting last accesses from third parties), and a summary of self-reporting data. This last one is divided between two modules that present the user basic health

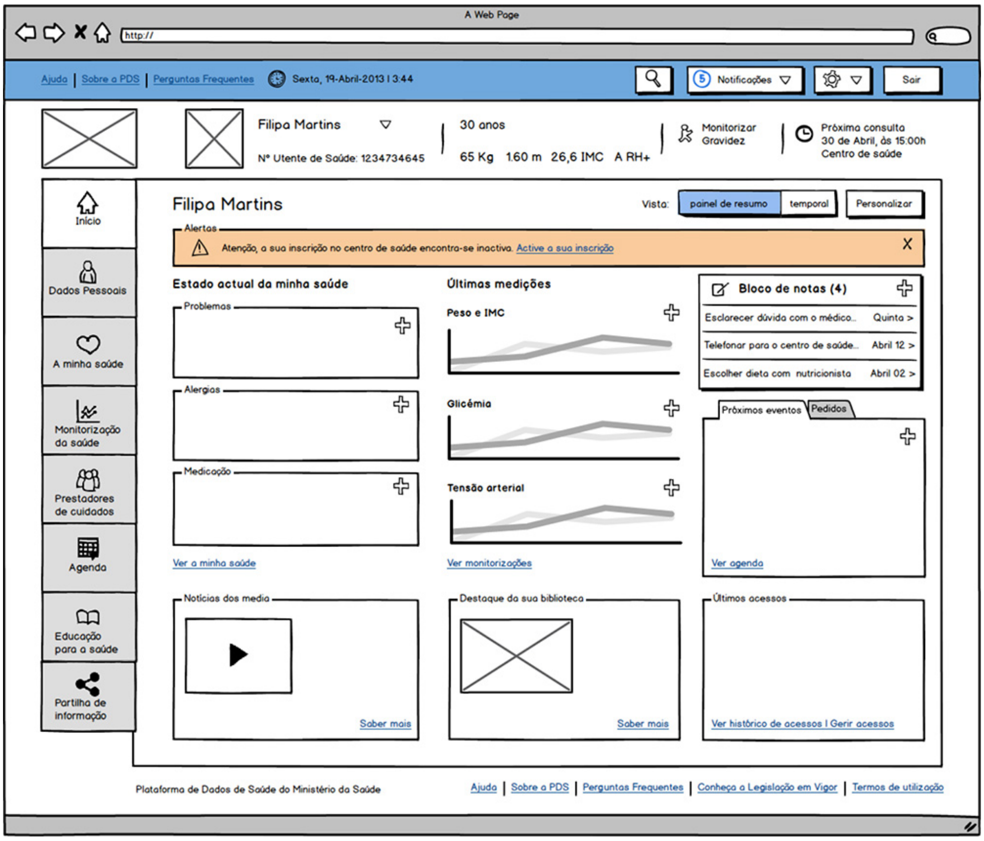

Figure 21: Dashboard summary view mockup.

information that connects to "My Health" section (problems, allergies, medication and habits) and "Last Measurements" (up to three last biometric measures) represented by sparklines that connects to "Health Monitoring" section. At the bottom of the screen the user can check the Library highlights and last news from Health Education section.

The "timeline view" (see Figure 22) shows the user interactions with the application, over time, chronologically. A timeline is displayed with the events history and all the records made to date, organized by the most recent. The user can filter by date and type of event: "eHealth services", "my health records", "self-monitoring measures", "scheduling events" and "user accesses". This view should be able to be customized by the user according to their feature preferences and clinical profile.

The header, which is common to the entire application, highlights important data that can be set by the user. By default the following information is suggested: name, age, the number of the NHS and photograph (personal identification data); weight, height, blood type and BMI (most relevant biometric data), shortcuts for specific modules of condition (e.g., diabetes or pregnancy) and components of decision support such as reminders for upcoming events. By clicking on the photograph, the user can switch between the user profile from the associated household family members, e.g., children.

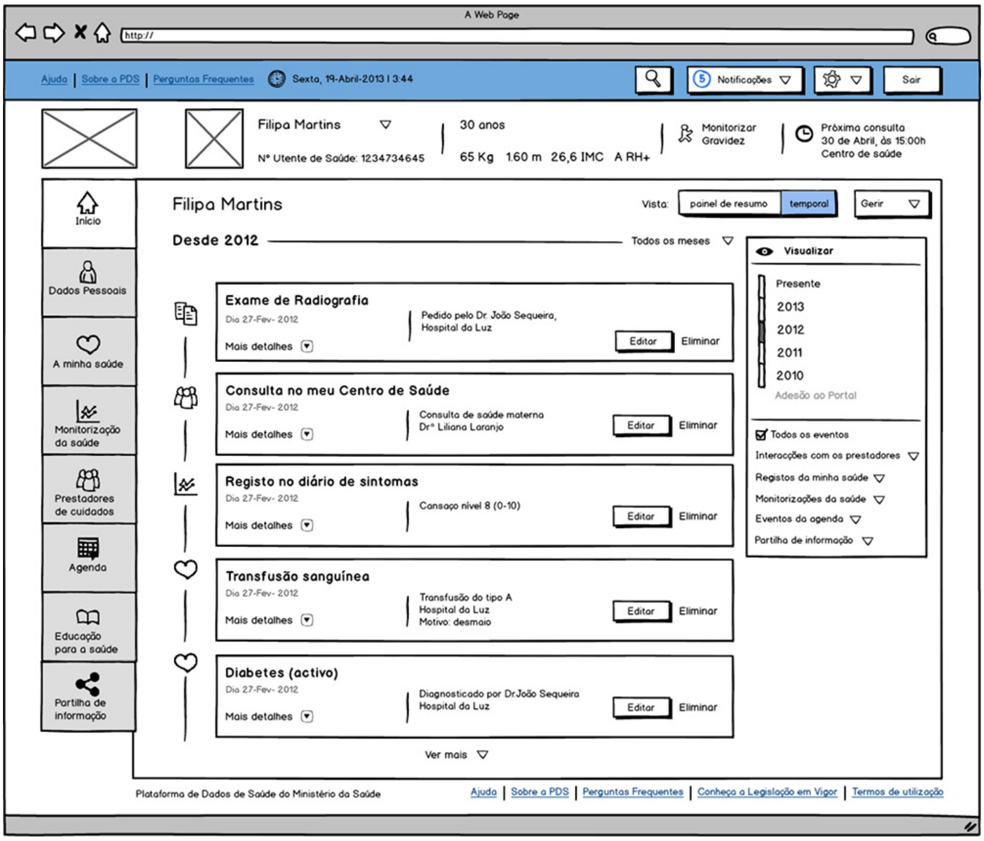

Figure 22: Dashboard timeline view mockup.

4.5.2.2. Personal data

The "Personal data" section (see Figure 23) is divided into the following sub-sections, to inform the NHS services about the personal information of the patient, also with features that set the user profile in the application:

> **General data:** records the user identification, basic health information (e.g., blood type), special needs (if the person is autonomous), personal contacts, family and social situation.

> **Emergency contacts:** in case of an emergency situation that requires the provider to call for a family member.

> **Registration in the NHS:** identification of the user in the NHS such as the unique identifier number; particular benefits the user may have such as prescription financial support and information about the primary care center

and GP that the user is allocated to.

> **Advanced directives:** records of end-of-life wishes of the person, such as care living will, organ donation and participation in scientific research.

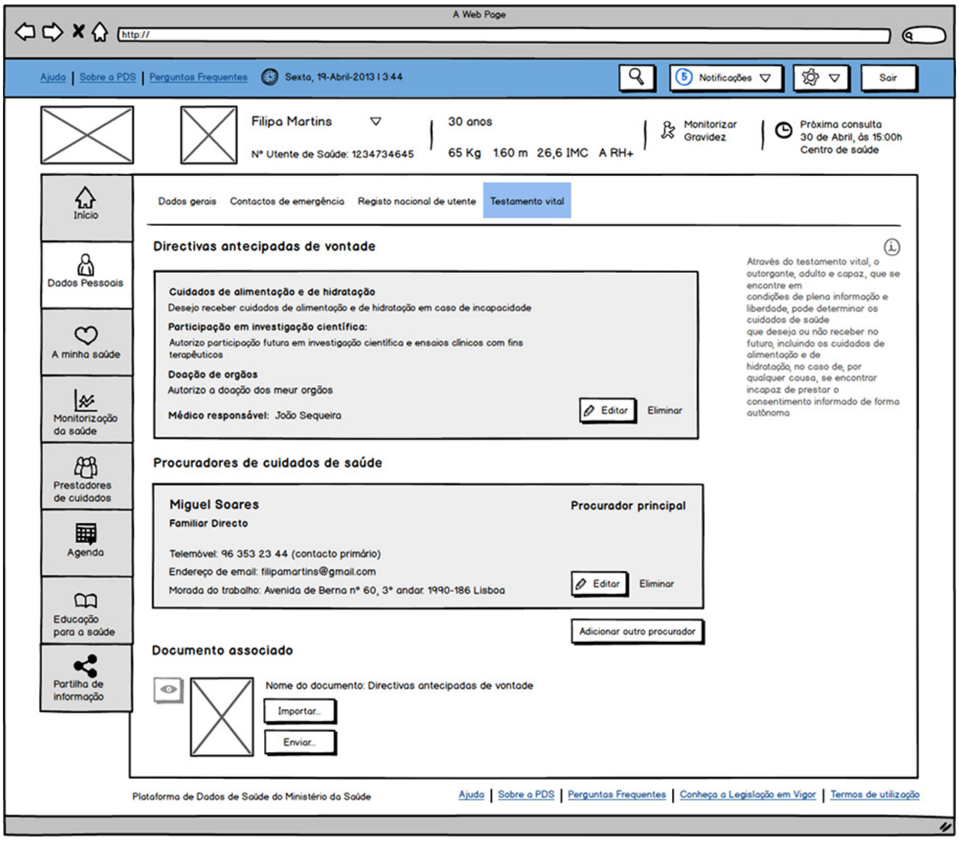

Figure 23: Advanced directives in Personal data mockup.

4.5.2.3. My Health

"My Health" combines self-collected data by the patient with data recorded by the healthcare providers from the NHS gathered in a unique summary care record (the user should be able to offer amendments to the record). The section is divided in "Basic information", "Health history" and "Summary care record".

In "Basic information" (see Figure 24), the user can report about their problems, allergies, medication and habits. As an example, see Figure 25 that shows the adding of a new medication. Problems can either be symptoms or diseases and should be searched in a given list [16] or manually inserted. If the problem is associated with pain, the user can set the intensity of the pain according to the typical visual analogue scale for pain (VAS Pain) throughout the time, and its location through a

16 In Portugal the list is validated by ICPC-2 (International Classification of Primary Care)

body diagram. The problem is associated with a status field that can be set as active, intermittent or past (and be filtered by these criteria), beginning and end date. The user is also asked if the problem causes functional limitations or affects the daily living activities such as sleep work or physical practice.

Allergies are defined by their type (to medication or other allergies), should also be selected in a given list and set in a date when they began.

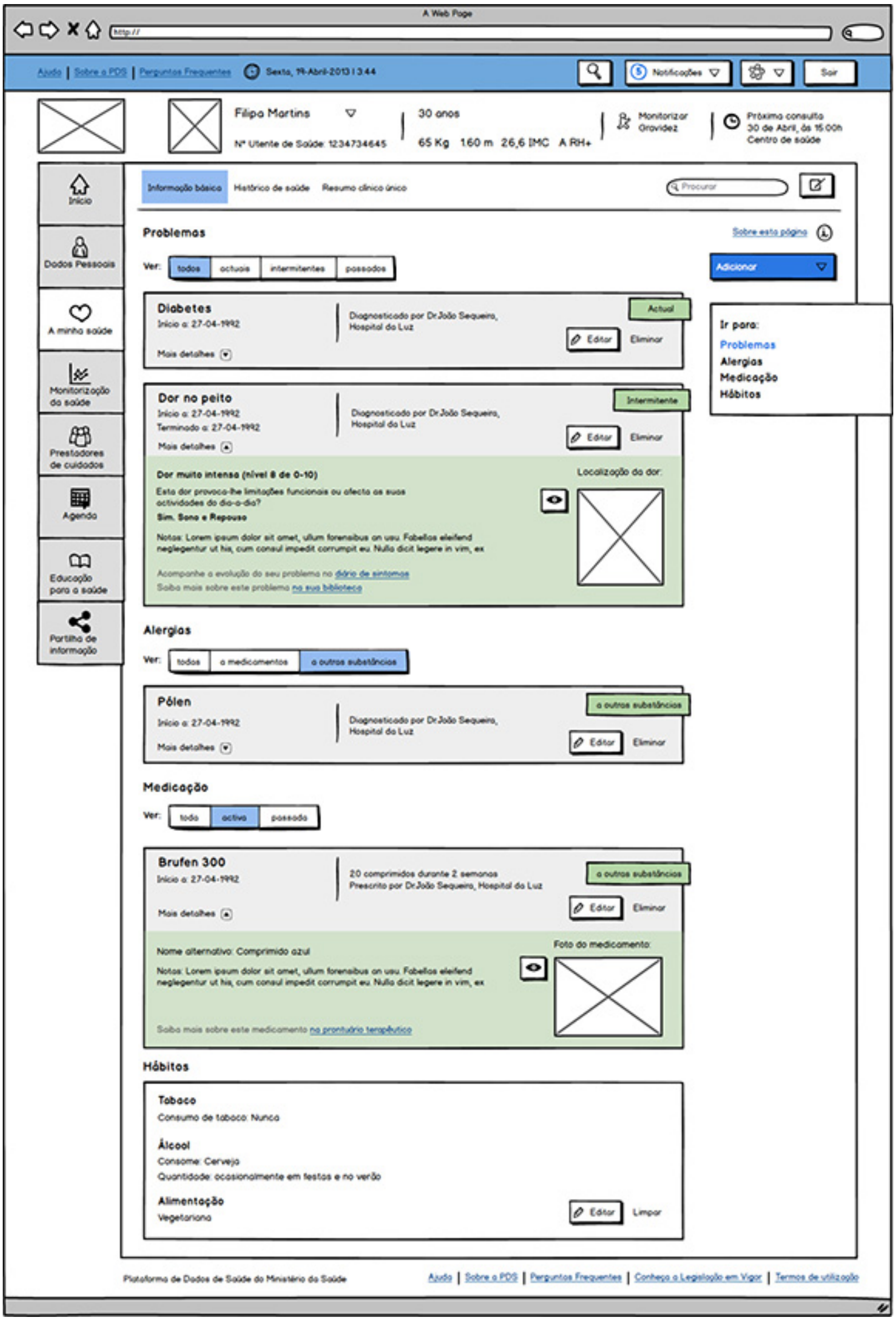

Figure 24: Basic information in My Health mockup.

Medication should be selected through a smart search through the National database [17] and be always up to date, showing the date from its last update. It should be possible to search by its active ingredient, besides the market brands. When adding a medication (to the system, after the selection from the appropriate list, the user must select the dosage, beginning/end date, (daily) frequency, duration, comments field and if it was prescribed by a doctor. In advanced information the user can give an alternative name to the medication like “blue pill” and insert its picture for a more user-friendly usage. Habits are concerned with food, tabaco and alcohol consumption.

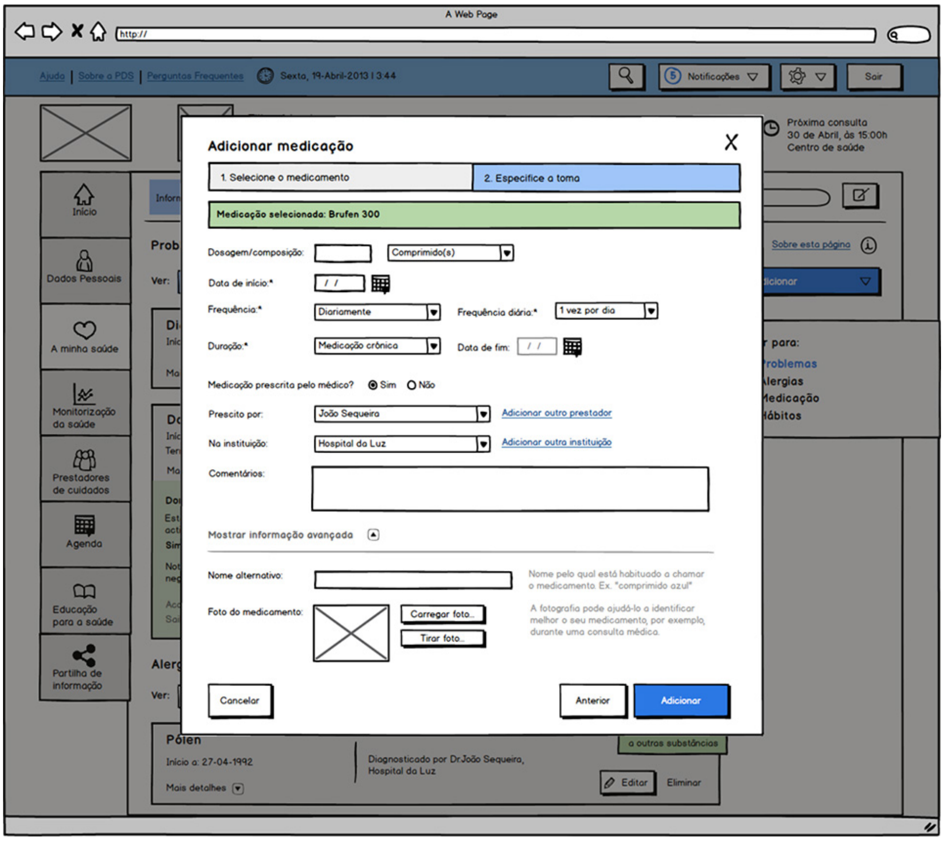

Figure 25: Adding medication in My Health Mockup.

“Health history” brings together all the patient history that can be reported by the patient, over time, within the following fields:

> **Exams and lab tests:** exam type, name, date, comments; the user should be able to upload the document reports, preview them in the system or send it to someone.

> **Vaccines:** NHS vaccination schedule with the possibility of quick insertion

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17 In Portugal is Infarmed: http://www.infarmed.pt/

of the National vaccine's plan.

> **Past medical appointments:** type of appointment, date, caregiver, institution and reason.

> **Procedures:** appropriate fields should be enabled according to each type of procedure, as an example for surgeries: type of surgery, type of anesthesia, date, caregiver, institution, reason.

> **Inpatient episodes:** time period, institution and reason.

> **Family history:** allow disease insertion for several relatives (father, mother, grandfathers, children, others) in free text.

> **Blood transfusions:** type of transfusion, date, institution and reason.

> **Accidents:** type of accident, date, local and consequences.

4.5.2.4. Health Monitoring

This area allows the user to collect their health data through self-tracking tools. It is divided into "Measurements", "Healthcare programs", "Health assessments" and "Health diaries".

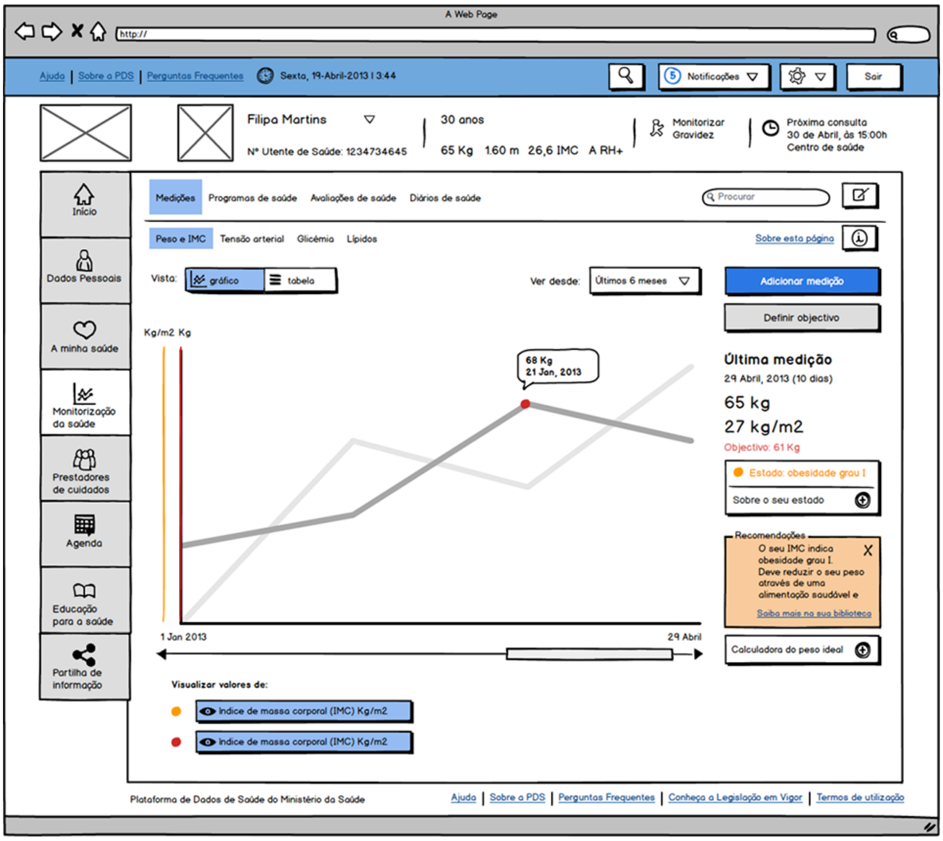

Figure 26: Measurements in Health Monitoring mockup.

"Measurements" sub-section (see Figure 26) includes the following measures: weight and BMI (the user should be able to set a goal to achieve and be engaged with reminders or motivational messages in the system), blood pressure, glycaemia and lipids (cholesterol). The data can be collected either manually or automatically if connected to sensor devices. Calculators that inform the user about the appropriate average of the reported biometric values. These can be associated with the measures of weight / BMI and glycaemia. The other two measures can have contextual help in order to inform the user about their values. Measures can be visualized over time, in two views: chart or table and filtered by date and period of time.

"Healthcare programs" consists on specialized modules to monitor specific health conditions or chronic diseases. Each program should provide specific self-management tools, recommendations and treatment best practices for the user to follow. According to the requirements for Portuguese Patient Portal, we suggested that the system should include the following programs: Diabetes, Pregnancy and Electronic personal child health record (ePCHR). As an example, the ePCHR module should include measures and charts for the weight, height, head circumference-for-age and BMI. It should allow monitoring the psychomotor development of the child and it must present a follow-up of medical visits and vaccines plan advised by the NHS.

"Health assessments" include quality of life score (any age); a geriatric assessment (above 65 years old) that reports the physical, mental and social functioning of the individual; and health risk assessments.

"Health diaries" include several types of diaries: a personal diary, where the user can write information in a daily basis in free text reporting about pending issues, to-do list or concerns. Personal notes could then overlap the interface and be dragged in any part, like "post-its", during the navigation in the application. A symptoms diary, where symptoms can be classified, e.g., duration, reported through VAS Pain scale (or other) throughout the time, be visually tracked and tagged in a body diagram. A nutrition diary, where the user can record the type of food and the amount of calories ingested per day. A mood diary, where the user can answer several types of questions that assess his feelings in a daily basis, e.g., How do you feel today? and map his mood during time, through several features that can be explored.

4.5.2.5. Healthcare Providers

In this section, the user can manage the eHealth services from the NHS available in the portal, in the following sub-sections: “My primary care center”, “My providers” and “Surgery registration”.

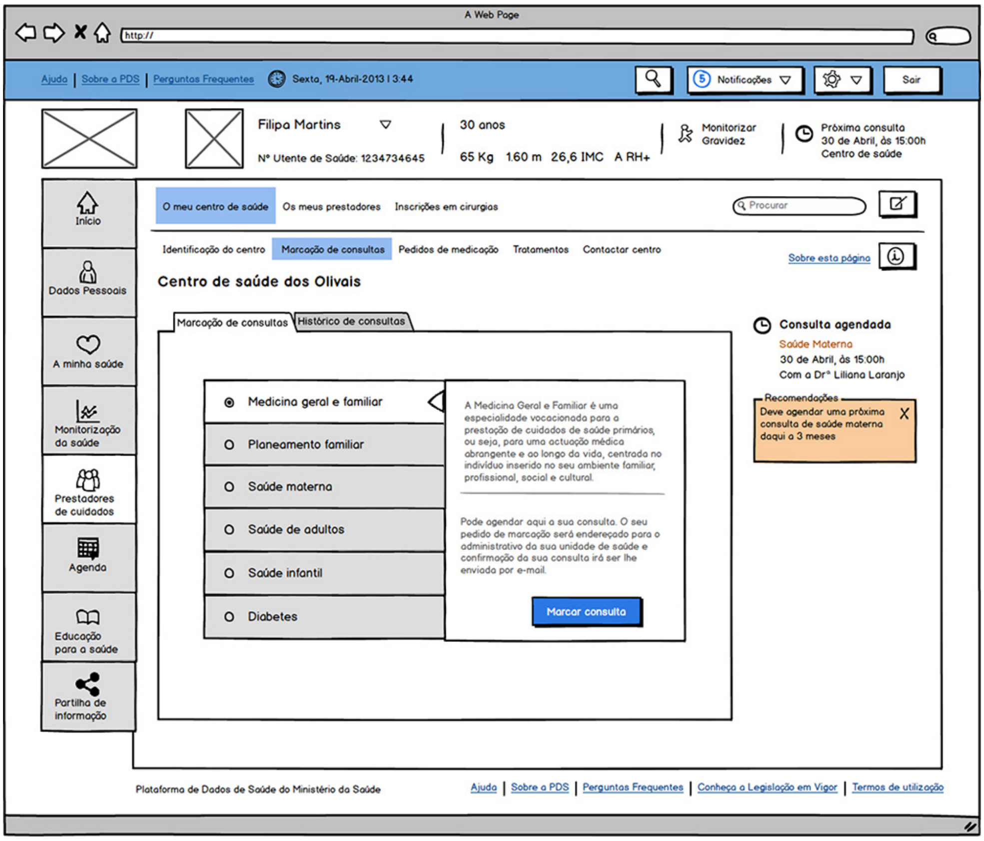

Figure 27: Schedulling an appointment in My providers mockup.

In “My primary care center” the system automatically displays the information about the center the user is allocated to in the NHS, according to his area of residence. In this section the user can interact with the services that are related to his providing center: schedule an appointment with the general practitioner (GP), (see Figure 27); access their past visits from the center; request medication renewal and check its status; access prescriptions history; access undergoing treatments; contact the center about any questions regarding their care plans, new symptoms or other issues that do not require an office visit; send a requested document to the providers.

In “My providers” the user can visualize a list of their GP as well as the providers who follow them and access their contact information. They can also find other providers and institutions from the NHS.

In “Surgery registration” the user can follow-up their surgery request status within the NHS position list and access past surgery requests.

4.5.2.6. Schedule

The schedule combines the scheduling of the different events within the application (e.g., future appointments or exams) and creates reminders for those events. Synchronization should be possible with other personal computer tools of the user such as Google calendar or Outlook.[18]

4.5.2.7. Health Education

"Health education" combines the following sub-sections for personal decision support, with the goal of improving lifestyle behaviors:

> **Health library:** the user should be provided with reliable educational materials about health domains, and access best practices for self-care.

> **Health glossary:** alphabetic index search tool.

> **Health News:** feed from media news.

> **Discussion groups:** allow users to interact amongst them, about certain health topics regarding their condition. The users should be able to use a nickname instead of their name.

4.5.2.8. Information Sharing

"Information Sharing" allows the user to manage their privacy control within the PDS platform ecosystem. This section is divided into "History access", "Access management" and "Send or print".

"History access" enables the user to check by who and when their personal record was accessed, what was the reason for the access and in which institution from the NHS it took place. The user can share their records in "Access management" (see Figure 28). Here the user can give permission to share their data with healthcare providers of the NHS (which by default is authorized by the system) through three levels of sharing: (1) regarding their PHR records, (2) their unique summary care record, either Nationally or abroad (within the European eHealth network), (3) share the data with a family member or another person (e.g., a caregiver that is not in the NHS). It is also possible for the user to create a profile in this sub-section, on behalf of a family member, e.g., children (until they reach 18 years old) or elderly

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18 Mockups were not provided for this section as they were not considered a priority for the proposal. The same applies to the next section of "Health Edutcation".

relative.

In “Send or print” the user has access to a list of all the PHR areas that they may choose to share partially or totally, with someone by email, or print them into summary records to take to a clinical visit.

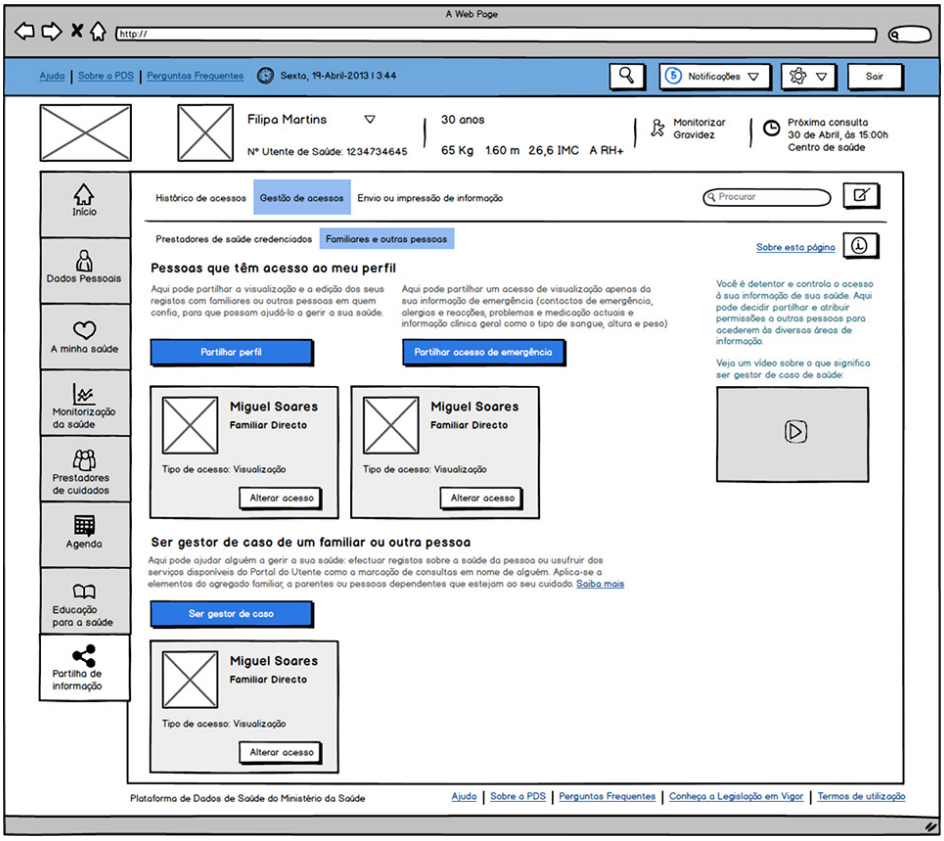


Figure 28: Access Management in Information sharing mockup.

4.5.2.9. Public area

The proposal for the public area of the Portal, applied the outcomes from backcasting (see Section 4.4.3) and has the following structure:

> **Home:** Landing page with several sections to provide an overview of the portal public area, which includes links to the each area and call to actions for registration (in the beginning and at the end of the landing page): (1) brief explanation about the Portuguese Patient Portal and its integration within the PDS, including a small documentary video; (2) list with the main functionalities of the Portal titled as “Know the benefits”[19]; (3) quick search engine for searching the nearest healthcare institutions to the user, from the

19 The request for health tax exemption feature had a quick button for a calculator so the user could simulate their taxes before they register or login.

NHS network; carousel with opinions of registered users in the portal; an area with latest news about health; an area with quick help of the customer support area; fat footer displaying quick links about how the portal works, other useful portals and phone call lines of the NHS and social network sharing buttons. See Appendix D that displays the visual design of the home landing page until section (2) and Figure 29 that displays the complete page, which was offcially launched.

> **How does it work:** provides content about the PDS, details all features of the portal; content to inform about foreigners living in Portugal and Portuguese living in the foreign; content about the benefits and rights of the citizens in the Portuguese NHS.

> **About Health:** content about news from the NHS and other relevant news validated by reliable sources of the SPMS; this area also provides a glossary about health topics that include treatments, lab and exams and health problems by specialty or body location.

> **Search Providers:** provides the user an advanced search about the nearest healthcare institutions to the user, from the NHS network, displaying the results in a map. The search include the different type of facilities either hospitals or primary care centers and pharmacies (see Figure 30, top).

> **Support:** enables content that help the user to navigate in the portal, frequent asked questions and short video tutorials. The section also provides a web form and a phone number to contact directly the support team.

> **Login:** the user is able to login in two different ways that are displayed clearly, side by side: on the left they can enter using the citizen identification card reader (in this case the user can have access to more confidential information such as the summary care record); on the right side the user can enter without the card reader, by entering their NHS identifier number and password (see Figure 30, bottom).

The several user interface proposals of the public area applied a different design methodology by enabling the team mockups closer to the final solution, including the visual design. A detailed guide style[20] was also provided to the team with all typography, color and layout specifications, including responsive design for desktop,

20 At this stage we worked with the designers of SPMS who participated in the guide styles specifications.

mobile and tablet views. More examples of the UI of the public area (print screens of the online portal) are displayed in the next section.

4.6. Prototype Development

After the creation of the mockups, the visual design of the main pages of the Integrated PHR was followed, to also inform the development of the prototype's look and feel (see Appendix E). The prototype of the Integrated PHR foundational design model was then developed as an HTML and CSS interactive template. The main pages that were developed are the application dashboard (see Figure 31), the presented in the following pages, "My Health" section (see Figure 32) and the "Monitoring section (see Figure 33).

As we wanted the PHR to be accessed in any type of device, we contemplated fluid and responsive layouts in our prototype, creating four main views: two for tablet, one for mobile and other for desktop (see Figure 34). To achieve a responsive design we used the Bootstrap framework[21]. In this scope, it is relevant to mention the importance of responsive design and the difficulties inherent in creating an application of this kind. Through responsive design we can achieve a cross-platform application with fluid layouts that adapt to any type of device screen. This allows a unique platform development effort without the need to create other extra applications. However, a responsive application involves more code, associated to the different possible views. As such, it is important to create a balance between quality and efficiency. This commitment is secured with simple transitions between different views, which we were concerned with, during the development.

Besides the prototype for the Integrated PHR that was delivered to the SPMS team, the redesign of the public area of the portal was launched in December 23rd of 2014 as a result of this research work. The public area was developed by the SPMS team also following a responsive design and is presented in Figures 29 and 30. The referenced figures of the prototype are presented in the next pages of this section.

21 http://getbootstrap.com/

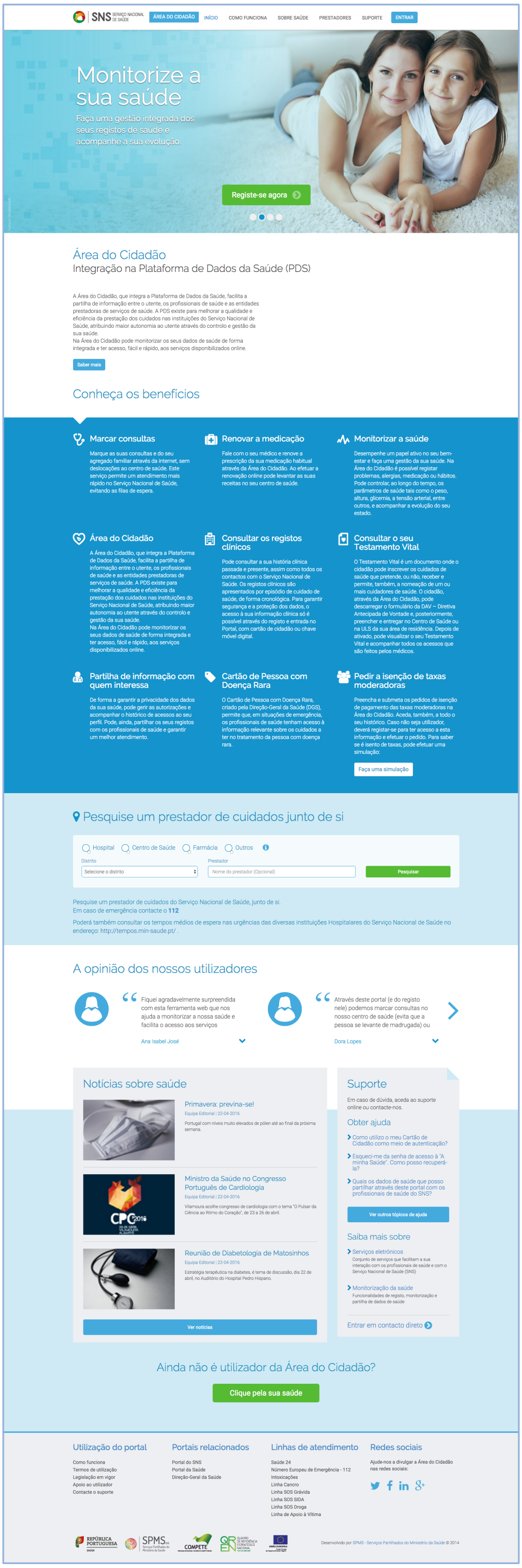


Figure 29: Complete home landing page from the online Portal.

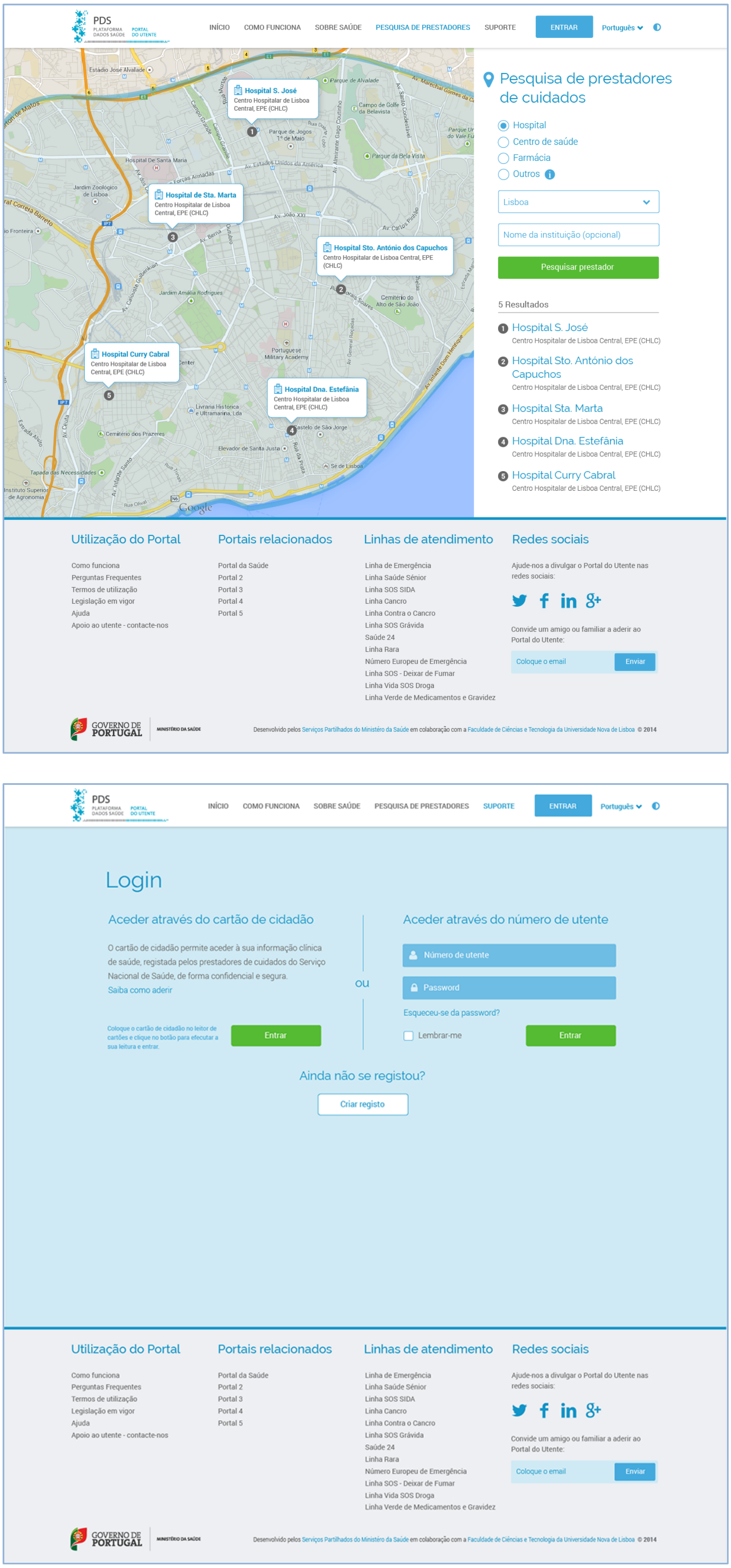


Figure 30: Search providers page (top) and Login page (bottom).

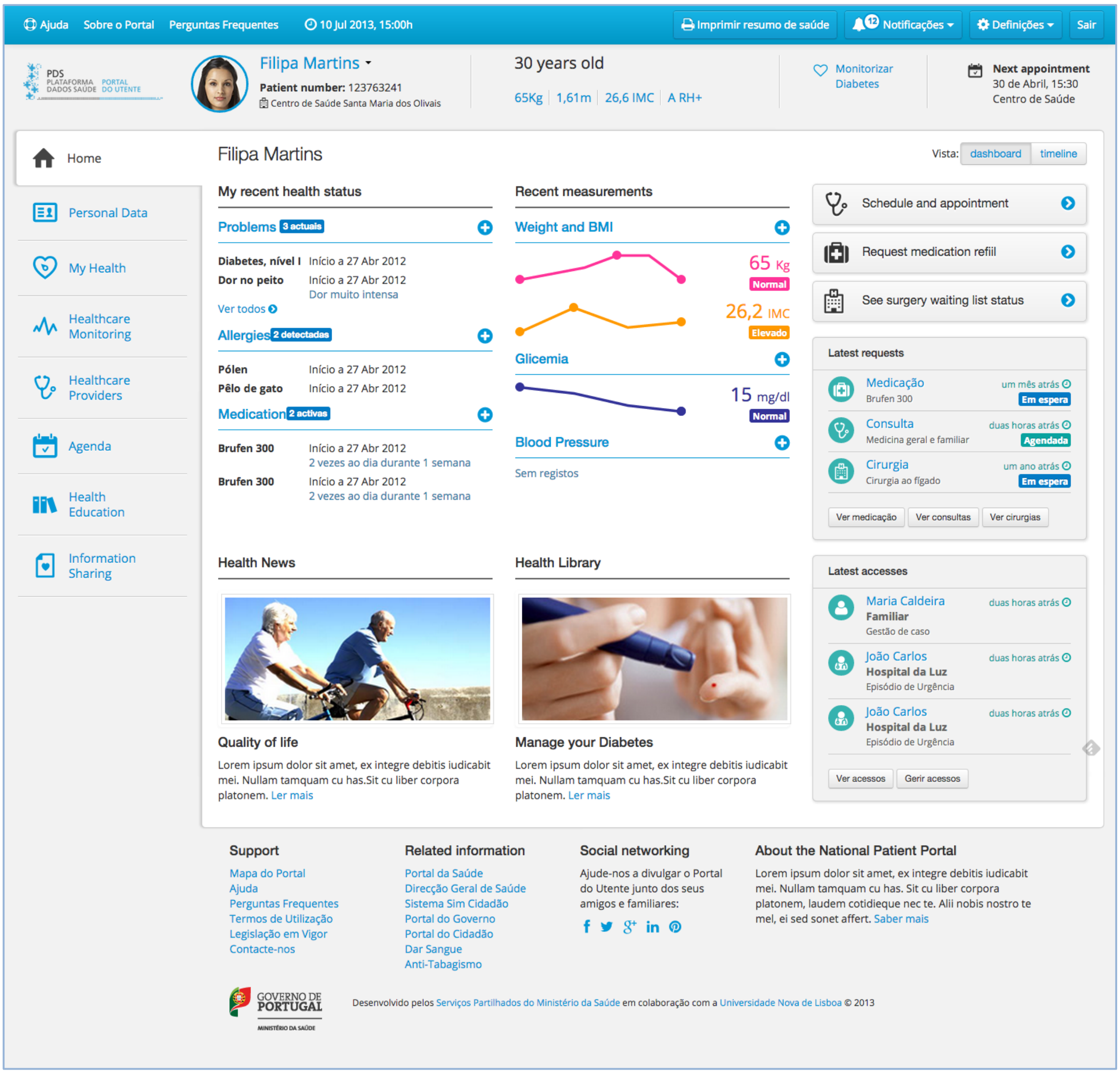


Figure 31: Application dashboard.

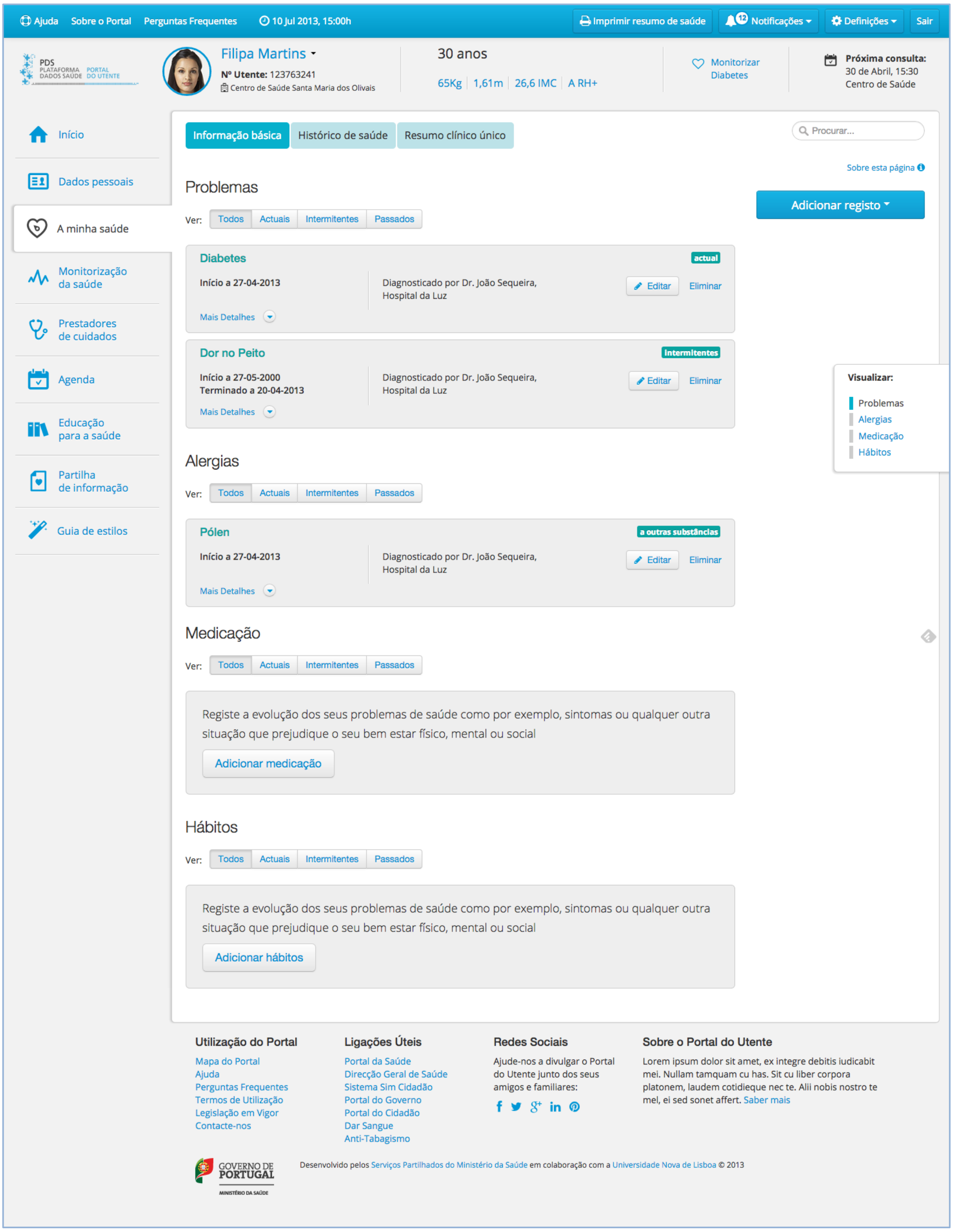


Figure 32: My Health section.

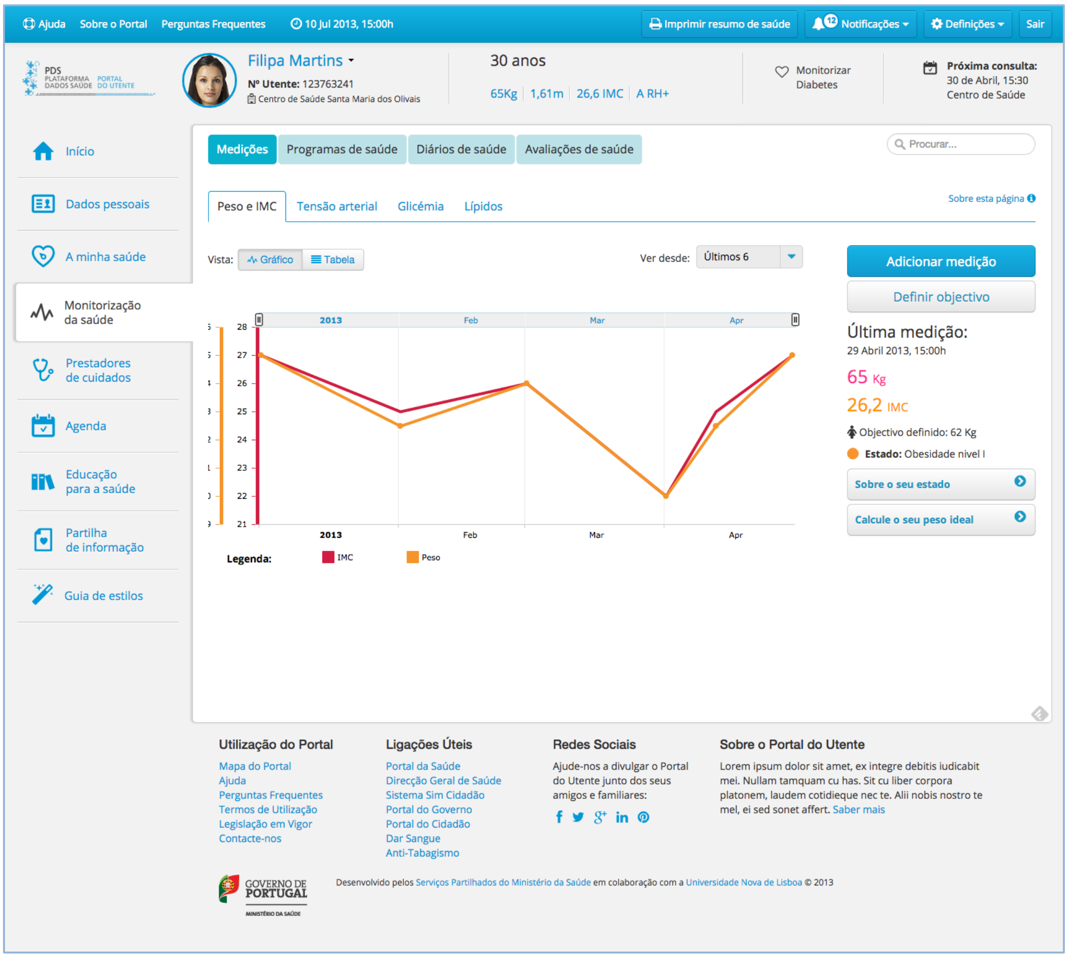


Figure 33: Monitoring section.

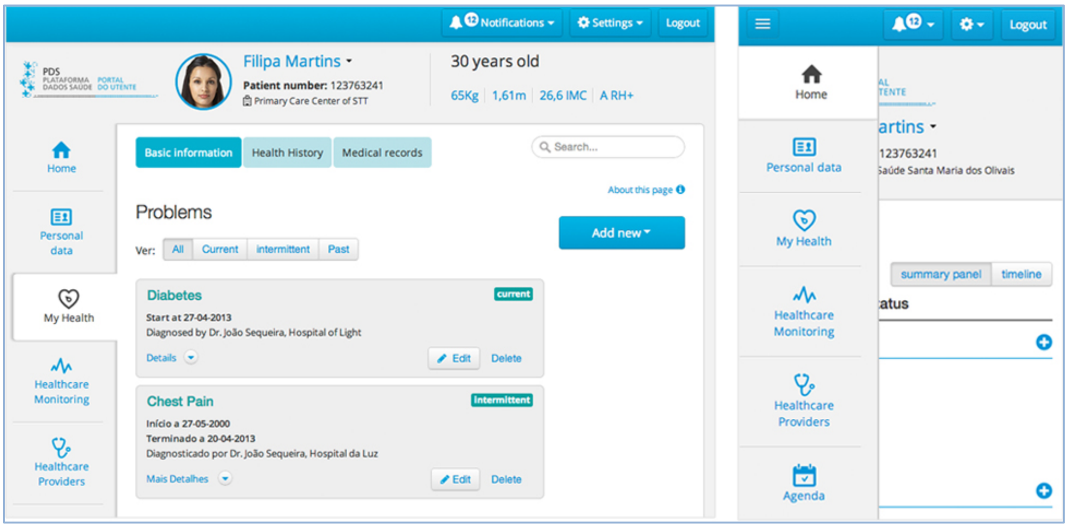


Figure 34: Application tablet view (left) and mobile view (right)

4.7. Results

The results of this use case aim to answer to research question Q1, of this thesis. The design of the Integrated PHR for the Portuguese Nationwide Patient Portal was accomplished, exploring several participatory design and UX methods that were conducted with the SPMS team. The understanding of the users behavior of the platform was a main focus during the research work process. The description of the design model proposal, user interface design and prototype development detail how health data from different sources can be combined in a new model in Health IT, the Integrated PHR, to improve the user experience of the citizen healthcare in this case, part of a Nationwide Patient Portal. The combination of different sources that are related to the portal, consisted on merging the most typical self-tracking tools from PHRs with eHealth service tools from Patient Portals, which in this case, enable the Portuguese citizen to manage their health and interact more easily with the NHS, within the PDS ecosystem, by exchanging data with the providers. Nevertheless, the Integrated PHR design model that derived from Part I of this thesis, can be extended to other studies that involve the design of any Integrated PHR and to other ecosystems that may go beyond the particular context of a Nationwide healthcare network, as it was founded on an extensive literature review. Also, the fact that the ecosystem of this use case covers a wide spectrum of users and development requirements, the reported results can inspire and inform other systems that can either be also widely or more locally deployed.

We provide within the model, a comprehensive structure and an information architecture that was validated by a significant audience of users, where it was possible to find out that mental models between younger people and senior people, are very similar; and that healthcare professionals understand eHealth features mainly as a way of sharing data with their patients, while patients understand them mainly as a way to manage their health. This dichotomy between "sharing the data" by the providers and "managing the data" by the patients, should be reflected in the design strategy for each specific user profile that accesses the integrated platform (provider or patient), in a way that the performed tasks in the system, can foster the patient-provider relationship.

☆ ☆ ☆

The second stage of this use case was concerned with enhancing the experience of the users within the platform. A user-centered design process combined qualitative and quantitative methods to find which design communication strategy could better engage the users with the Integrated PHR.

The answer to a simple question how far in the future will we start from? – in the beginning of the backcasting workshop with the stakeholders, allowed us to align goals and desirable futures for the improvement of the emerging Nationwide Patient Portal within the PDS ecosystem. The work began with the redesign of the public area of the Patient Portal with a timeframe from 6 months to one year. Soon enough the team members realized that to achieve the desirable futures, they needed to better understand their users. The study has then presented an analysis of the differences and characteristics of the several user groups that take part of the user experience of the patient portal. They are a result of cross-analysis of the user's online behavior with the feedback given by the stakeholders during the interviews. By the end, current and potential user groups were defined by their affinity level (main goals to access the platform) and by their engagement level, accordingly as: (1) general public (interested or first-time use); (2) active adults (regular use); (3) people with long-term conditions (regular or passionate use); (4) householders (regular or passionate use); (5) senior people (regular or passionate use); (6) children and grandchildren (regular or passionate use); (7) underrepresented population (unaware); (8) foreigners (unaware or first-time use) and (9) wellness group (regular or passionate use).

While the combination of the stakeholders interviews and web analytics methods helped to broadly clarify all the user groups that the SPMS development team should design for, backcasting had a major impact in finding solutions for the user groups: (1) general public, (2) foreigners and (3) underrepresented population. For user group (1) all benefits of the platform were clearly explained in a summary of functionalities and a new area of geo-referencing to locate healthcare institutions was provided in the portal. For user group (2) a specific area was created to welcome this population with guidelines to follow on how to belong to the Portuguese NHS. For user group (3), the Ministry of Health and SPMS team decided a way to support this population through public attendance located at governmental citizen stores. Here, a site administrator can access the portal at the citizen store, on behalf of someone else, e.g., a foreigner who needs to use an online service of the NHS.

Interview findings revealed strategies from the team to diffuse the value of the portal through other touch-points within the NHS service, such as conducting marketing campaigns in primary care centers. They also provided insights regarding what have been the hurdles of the platform use (e.g., access the summary care record from the providers) and new ideas on how to improve the user engagement including data privacy, telehealth appointments or health and wellness promotion.

Customer support feedback helped profiling mostly the user groups of active adults (2), seniors (5) and children and grandchildren (6), as many of these type of users from the portal, contact the team on a daily basis, reporting their limitations with the usability of the portal, also sharing desirable features. Interviews also inspired the creation of the potential wellness user group (9), which in the future can engage younger people and sport lovers, into the platform. Statistics showed that women are the most typical users of the portal. This stands accordingly with literature that shows the importance of the women role on the family health management [104].

Figure 35: Celebration of the Public area redesign presented at a "Forum on Healthcare Innovation" in April 2015.

According to this last user-centered design study, the public area of the Portuguese Nationwide Patient Portal was launched in December 23rd 2014. A previous celebration before the launch, took place in a "Forum on Healthcare Innovation" on the 7th to 8th of April 2015, organized by the SPMS and the Portuguese Ministry of Health (see Figure 35).

The structure, content and information architecture of the public area was created from scratch. The portal became responsive and accessible in any device. All planned activities of the follow-up agenda that emerged from backcasting were implemented, except for the ideal state of building a "unique cross-channel experience". Despite the solid approach that this state could bring, its development time was considered to be overwhelming at that time. For that reason, in a first approach, the other portals from the PDS were kept independent from the Patient Portal. As a result, the portal new user registrations nearly doubled on the month next to the launch, from around 500 to 1000 monthly registrations, stabilizing at 800 registrations per month. The portal reached nearly 971.000 of users (excluding the household family members) by April 2015 (see Figure 36), which demonstrates a boost of new users.

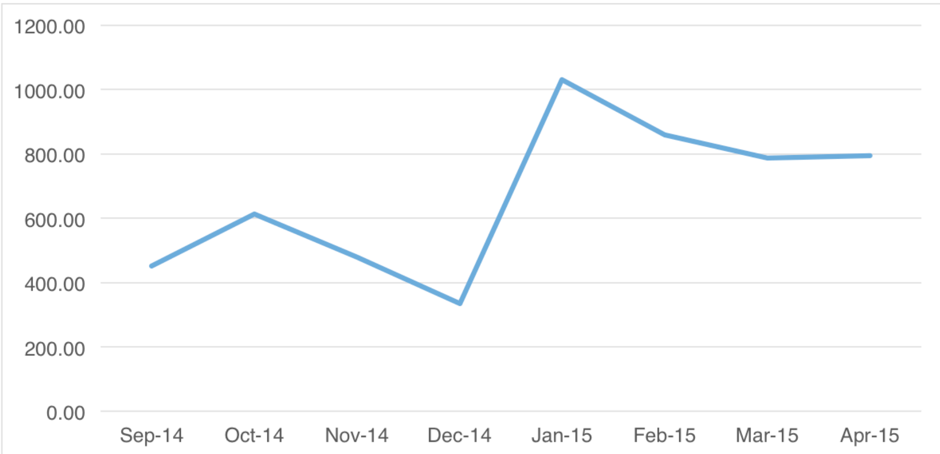


Figure 36: New registrations in the Patient Portal three months before and after the public area launch in December 23rd of 2014.

Meanwhile, the desirable future of a "unique cross-channel experience" was later applied by February 2016, but with a different layout, designed and implemented by an external party to this research work, with new features that were later added, according to the incoming milestones that the SPMS team is subject to.

To conclude the results, whilst the public area achieved its final implementation, contributing to the improvement of the communication and accessibility of the Portuguese Patient Portal, the application of the Integrated PHR that was developed during the lifetime of this research work, did not yet achieved its implementation in collaboration with SPMS. However, we expect that the design model can inspire the team to keep improving the portal in a near future, also informing other similar efforts regarding the design and implementation of Integrated PHRs that take part of the user experience of Nationwide Patient Portal networks.

PART II

The Portuguese Nationwide Senior Telehealth Program

5.1. Use Case Scope

Social isolation is exacerbated by ageing, as growing old makes people more vulnerable [140]. Interestingly, just as social isolation is growing, so too is the use of the Internet by elders [24]. Older adults are a fast growing group of Internet users that use communication and social network features such as Skype or Facebook, also demonstrating other online interests [8]. The way seniors behave online was previously described in the literature review of this thesis, Section 2.7.

The World Wide Web's capability to provide unprecedented access to high quality health related information and to mediate interactions between healthcare providers and patients, paved the way for telehealth and related services, to bridge the gulf of accessibility in the delivery of quality care [14] [82]. The changes in abilities that result from the ageing process are what turn older adults into a target group that could benefit greatly from access to telehealth services. At the same time, it represents the cause for the extra attention required when designing these services [25]. Telehealth communication has the ability of connecting seniors from a wide range of socio-economic statuses [123] with healthcare providers, with the possibility of also involving their families [183]. Telehealth as an assistive technology for senior people was also previously described in literature review, Section 2.5.

Comprehensive geriatric assessments play a crucial role in the design workflow of telehealth programs. It consists of a process that determines the person's medical, psycho-social, functional, and environmental resources and problems, creating an overall plan for support and follow-up care, with the goal of improving wellbeing [184]. However, despite seniors being aware of their wellbeing is proven to be beneficial, its measure and consideration is often overlooked in the design cycle of technology [46]. Several studies address how wellbeing can be assessed and visualised by older adults. Although it can be a challenging task, as it depends on the nature of the complexity of healthcare data [97]. While physiological and functional wellbeing can be captured using vital signs, social wellbeing (i.e., quality of life and instrumental activities of daily life), can be measured using social support networks and perception of isolation [72]. Further details about the way the senior wellbeing can be addressed through self-tracking tools that provide integrated visualisations, can be found in Section 2.6, in the literature review of this thesis.

Self-tracking tools for healthcare and wellbeing typically take part of PHR solutions having the ability to collect, analyse and display the data to the users, over both short and long term, important to increase user awareness. Nevertheless, the degree of burden of using these tools must not dramatically outweigh the potential or perceived benefits in healthcare outcomes both for seniors and providers who follow them. Research directions to foster the adoption of PHRs by senior people are described in Section 2.4, in literature review. The design of Integrated PHRs has the potential of enhancing the experience of senior telehealth programs by combining self-collected data from the participants with follow-up geriatric assessments and care plans that are applied on those programs by the clinical staff. Nevertheless, this model needs to be studied in the context [40], analysing how the this type of community services can benefit from Integrated PHRs.

5.2. The Portuguese National Senior Telehealth Program

This use case explores the design of an Integrated PHR applied in a telehealth environment for a senior community, based on the foundational design model that derived from the previous use case of this thesis. It describes the design strategy of a cross-channel user experience for the seniors of the Portuguese National Senior Telehealth Program. The proposal is designed to augment, not replace, the original service, by combining the current phone line with a new web channel that integrates a web app for tablet view, complemented with an Android app developed for a smartwatch. The solution described in Part II of this thesis, encourages users to work together with the nurses from the program, who follow their wellbeing periodically over time, through multidimensional assessments.

The Portuguese Senior Telehealth Program - "Saúde 24 Senior", was launched in Portugal, in April 2014 and followed by the beginning of this study (2015), a total of 24.000 individuals over 70 years old (with the goal of extending it to the age of 65). The model of care consists on assessing the overall health status and both environmental and individual domains related to the autonomy and wellness state of the individual. To accomplish so, nurses communicate with seniors through regular phone calls, shifting from weekly to monthly follow-ups, by asking questions through guided assessments. According to the answers, an individual care plan (ICP) is automatically displayed to the nurses with associated recommendations.

The program aims at identifying and preventing frailty, risk behaviours, minimising social isolation, promoting healthy behaviours and contributing to a feeling of self-control and confidence among the elderly. The program is based on a bio-psycho-social approach developed to include an innovative and comprehensive geriatric assessment tool that addresses the physical, mental and social wellbeing of a person and their complex interactions [158], which is detailed in the next section. To be applied in a cooperative telehealth environment, the tool was adapted from its original version and simplified, so the program could assess the seniors through a phone line. Assessment algorithms for the macrodimensions of Autonomy, Health and Social, are stratified in microdimensions (as an example, the health macro dimension is subdivided in health status, presence of chronic diseases, medication, nutritional status, smoking, alcohol and other addictive drug habits) that are presented in a global health assessment (GHA) that gives rise to an ICP. This is automatically displayed in a system to the nurses in a summary and through a visual diagram that identifies frailties and selects an appropriate set of recommendations, when necessary. The ICP also presents the subsequent assessments that should be performed by the nurses in the next calls, according to the results. This allows the person to be followed over time, according to an initial evaluation that determines the priorities of the follow-up care, according to their needs. After the evaluations, recommendations were only shared during the calls, which seniors tended to easily forget. Initially, the program also planned to share the results with the seniors through a printed-paper to be sent by mail (which did not become implemented). Exclusion criteria for the program are: (1) hearing loss, (2) language constraints and (3) inability to answer the phone, due to severe disability. As the human aging process is associated with the prevalence of such conditions and hear loss [8], it raises barriers for seniors to enrol in the program, which ends to be contradictive. As such, the goal of this research is to reach a large number of seniors through a complementary online channel that may foster the engagement of seniors into the program.

5.3. Geriatric Assessment Model

The geriatric assessment applied in the Portuguese Nationwide Senior Telehealth program is based on a method called MAB – Method for Assessing the Bio-psycho-social, developed by a physician during her PhD and improved by her over time [158]. This tool is currently the most used for the evaluation of the geriatric population in Portugal. MAB is a multidimensional assessment tool, aiming to create standard guidelines for the detection of functional, physical, mental and social disorders of senior people, generating a corresponding ICP to address the detected failures. The MAB spans three assessment areas that allow to evaluate the ability of individuals to live independently: (1) health and functional status (bio); (2) mental state (psycho); and (3) socioeconomic context (social). Each area is composed of several domains (see Table 2). Each domain have a set of assigned variables. Some of these variables are further subdivided into specific categories or items, which add up to a total of 56 questions.

The way the evaluation is performed is by assigning values to a given number of variables, per domain. The scoring is done on a scale that can have up to four levels, depending on the variables: they can either take the values 0, 1, 2 and 3, or only the values 0 and 3. While the quotes 0 and 1 represent an unfavourable result, quotes 2 and 3 represent a favourable result. The score of each domain is then generated by calculating the mean values of the variables (e.g., falls) or by choosing the smallest value among several variables (e.g., complaints of health and locomotion), depending on the domain. After the calculation, the bio-psycho-social profile of the individual is represented by a sequence of digits of the classification for each domain.

BIO	PSYCHO	SOCIAL
Gender	Cognitive status	Habits
Age	Emotional complaints	Social status
Falls		
Locomotion		
Health complaints		
Instrumental Autonomy		
Physical Autonomy		
Nutrition status		

Table 2: MAB tool - Method for Assessing the Bio-Psycho-Social Wellbeing of the Senior

5.4. Research work

The goal of this research work is to create a digital solution to foster the engagement of the senior population in the program and also to extend accessibility to those currently excluded, through a web channel that consists on an Integrated PHR. The proposed system aims not to replace but to complement the current service of the phone line of "Saúde 24 Senior" program. By defining a design strategy to combine phone, web and sensor devices, this research demonstrates how the Integrated PHR can be an enabler of coordinated care in this context, explaining the benefits of having a cross-channel user experience in a telehealth environment. This type of user experience can contribute to a more continuous and personalised follow up care within the senior community, helping to decrease the burden of attendance needs that currently exists in the NHS healthcare services due to the demanding ageing population and its prospects.

The design and development of the Integrated PHR called as 'H24 Senior app', followed a multidisciplinary research approach in collaboration with LCS (Linha de Cuidados de Saúde), a private organisation that worked for the Ministry of Health and was responsible for the deployment of the program. The work was based on qualitative, generative and field research, applying interviews, ethnographic and participatory design methods with the stakeholders of the program and the seniors. Generative research collects data from participants such as contextual inquiries, which are very useful to explore the mind of someone doing certain task(s) [222]. It focuses on a higher level that evaluative research which applies other techniques such as usability testing, card sorting or customer feedback. Contextual inquiries are an ethnographic interviewing technique based on a master-apprentice model of learning, where the interviewer puts itself as an apprentice to learn from the users [31]. This method is also useful to gather information about things or processes that cannot be observed effectively by other means [103].

The system was designed to:

1. Enable seniors to access their care plans and recommendations;
2. Provide related health educational material;
3. Enable self-tracking tools such as symptom or mood diaries (sharing with the nurses how they feel on a daily basis) that may help to monitor daily health adverse events prematurely, between the follow-up calls;
4. Enable reminders and motivational messages for practicing the recommendations, also giving providers real time feedback on how they are addressing them;
5. Offer a more personalised attendance in the program by profiling the person during the registration process;
6. Allow seniors to share their data from the program with their family (to follow their condition) or their physicians;
7. Manage scheduled phone contacts to avoid missing calls;

8. Provide to the seniors, global health self-assessments before a scheduled phone call. This allows nurses to better prepare themselves for the follow-up, encouraging the program to establish a conversation rather than an inquiry, assigning a greater availability of time to discuss specific needs of the seniors;
9. Show opportunities to include people that are currently excluded from the program due to severe hear disability.

We began the study with user research, conducting a qualitative study with the program in the facilities of LCS, gathering the perspectives from the several representatives of stakeholders from the Nationwide senior telehealth program by conducting interviews with the following groups: seniors (followed participants), nurses (phone-call communicators), physicians (conceptual team) and the program manager. Accordingly, participants from the study were asked about what were the major concerns in the current service (focusing on communication issues by phone); if adopting a complementary web-channel could be of their interest, according to the needs of each group; how both channels (phone and web) could be integrated into a more effective service cross-channel experience. Other concerns are also addressed, such as how access to the ICPs should be displayed to seniors and how PHR data could complement the patient decision support of the nurses. Then, the design of our solution was sustained on a functional analysis that derived from these findings, and based on the previous extensive literature review from Part I of this thesis.

The functional analysis described all system requirements in order to form the prototype, which was validated by the responsible physician of the concept clinical team we worked with. After having the functional analysis approved, we were able to design a user interface (UI) proposal for the application, which was also further validated through participatory design sessions, held with a group of nurses and physicians. Likewise, we also worked closely with the original author of MAB, to adapt the tool into a self-assessment perspective, to be used by the seniors.

In parallel, the base structure of the prototype was being implemented trough an agile methodology: the proposed changes from the reviews were incrementally added to the application over time. The prototype was developed by Gonçalo Dias da Silva, an engineering master student who completed his master thesis titled as "Sistema Web para Programa Nacional de Telemedicina" in the scope of this use case research work.

To conclude the study, the user experience of our proposal was assessed by conducting usability testing with a sample of current and potential users from the program. Usability testing was planned to be formative rather than summative, to help forming the design and usability of the prototype, also in collaboration with the master student. As such, we chose to focus the method on desirability of adoption (qualitative research) rather than task completion success or usability errors detection (quantitative research). The goal was to understand if the users were willing to adopt and be engaged with the application, whether they found the features meaningful and whether they would make use of them. Nevertheless, quantitative research was also recorded and will be taken in consideration for final implementation.

The present study represents a relevant scientific contribute by providing valuable information regarding a telehealth program for senior people, which may lead to better programs and also inspire the design of integrated PHRs within the context of telehealth multi-channel environments.

5.5. User Research

This chapter details the methods that were described in the previous chapter of the research work of this use case, as well as the results that were obtained.

5.5.1. Stakeholders and seniors Interviews

With the goal of gathering the design specifications for the development of the Integrated PHR, semi-structured interviews were conducted with a sample of the several stakeholders from the program: 7 seniors, 4 nurses, 2 physicians and the program manager. The structure of the interviews can be found in Appendix E. All interviews were audio recorded and transcribed. We applied an inductive approach for qualitative data analysis [191].

In Portugal, only 9.5% of individuals above 65 years old have completed secondary education. Since low levels of education are quite often associated with low computer and Internet literacy, we did not use a representative sample for the seniors. Thus, we recruited a sample of well-educated seniors, as representative of the potential users of the solution. Likewise, it is likely that older adults will be more proficient in computer use, in the near future [69].

The recruitment of the seniors was led by the nurses during the routine phone-calls conducting the following predefined inclusion criteria: educated people with at least a high school degree, computer and Internet regular users. All participants were voluntary and agreed to participate in the study. During the interviews the majority of the seniors answered all the questions openly and went beyond the provided questions by sharing related life episodes and experiences. Interviews lasted approximately 40 minutes.

From the 7 selected participants, 4 were female and 3 were male with a range of ages from 72 to 89 (mean age=77.7); 3 had secondary school and 4 had a graduate degree; 3 were married, 3 were widows and 1 was single. All of them lived in urban areas, either cities or towns, 3 lived alone, 4 lived with their partners and 3 did not have any children. Their occupations before retirement were varied, ranging from physician, social security employee or army officer. Despite being retired, most of them were still active in their daily life activities. They expressed their interest in looking for information regarding health, taking in university courses and in political activism.

The interviews with the seniors were conducted through Skype, except for two face-to-face interviews. Interview insights were provided based on the raw data gathered from participants that reported the current program experience and evaluated their interest of adopting a web channel with an integrated PHR, exploring which information was meaningful and how it should be displayed to them. The interviews with the other groups (nurses, physicians and the program manager) were ran individually, at the agency office, lasting about one hour each. All nurses interviewed showed enthusiasm to collaborate with the goal of this research. We wanted to understand the difference between the perspectives of the nurses, who have been in the program for a long time, are more knowledgeable and have stronger relationships with the seniors, compared to nurses who had recently joined the team, who are expected to be more concerned with understanding the program functioning. We thus selected nurses who have been working in the program for different durations.

The interviews of the physicians were focused on analysing how the geriatric assessment MAB tool was adapted to a telehealth environment, in this case a phone line and how it could be applied in the Integrated PHR to be used by the seniors. The interviews were conducted following a “brainstorming” approach, questioning the functioning experience of the program. We challenged both nurses and physicians to think about the integration of the phone channel with the potential online-channel, also analysing which PHR tools could provide better data to the service providers.

The program manager interview was mainly focused in the phone-line initiative, strategic goals and integration with other services of the Portuguese NHS. Moreover, we also asked the participant to think about the outcomes that could result from the online channel, which by the end was seen as nearly being aligned with the future strategic goals of the roadmap of the program.

In summary, findings from the interviews are grouped by several categories that derived from a detailed qualitative data analysis to understand the following:

- How the program was created;
- What are the senior user groups that take part of the program identifying the ones with the most potential to adopt the Integrated PHR;
- What has been the phone-line experience and how personalised care can be accomplished through a cross-channel solution;
- If assessments should be enabled to seniors (if they also wish to perform them) and how they should be displayed.
- What is the role of family participation in the program;
- How both channels (phone and web) could be integrated;
- Which PHR tools could better support seniors in the web channel, engaging seniors in a more complete service user experience.

The results are grouped according to the relevancy of the roles of the participant groups, for each category and are presented as followed. Groups are refered as: Program Manager, CN# (Communicator Nurse + participant's number), S# (Senior + partcipant's number) and P# (Physician + participant's number).

5.5.1.1. Creating a specialized nation-wide telehealth phone-line for senior citizens

Program manager: According to the manager, the program was created initially as an inbound line. That means that if someone called with a symptomatic situation, depending on its severity level, it could be forwarded either to a hospital or to a primary care centre. However, the program manager explained the need for creating a new line for senior people: "In the screening process we found out that there was a group of major importance that represents one third of the population who regularly called us and who did not require any of our services. Instead, they asked for clarification about self-care procedures, so they could deal with their symptoms at home. As such, we thought it was worth it to have a more preventive attitude for the population risk groups and for that reason we created the Health 24 Senior, the first specialised line of our program." The new line was created as an outbound line (the phone calls are made by the personnel of the program) and has established protocols with other services of the NHS such as the community units' care centres spread across the country that can support seniors in vulnerable situations. By the time of this interview, the program was following-up a cohort of 24.000 seniors with an average of 1500 calls performed per day and an average of 150 received daily registrations.

Nurses: Initially, nurses invited people through phone-calls that were already part of the initial database. Afterwards, they evaluated if the individual's condition could fit in the program: they need to have some autonomy, being able to manage their basic daily activities, use the phone, not being bedridden and have some level of mobility (people in wheel chairs are also excluded). After an assessment of the cognitive status, they also check eating habits, physical activities, and health history. If the individual fulfils the requirements, he/she is followed within a periodicity time of 15 days.

5.5.1.2. Identifying senior user groups

Nurses: Participants mentioned the contrasting senior profiles they attended, which can vary either between people with low literacy (group A) or high literacy (group B) levels. In what concerns group B, CN2 states that they are usually married, living with their partner and have children. Many of them (both women and men) use computers and social networks like Facebook, which they like to mention. CN4 estimated that this group is about 25% of the total amount of the program attendees. The majority stated that group A does not have any family support, lives with financial needs and in complete isolation. CN1 commented: "There are people that because of their isolation or mobility constraints do not leave their homes and are in a very depressive mood." CN2 also commented: "We get many people living in rural areas between 75 and 80 years of age. Some of them are hesitant about the program and say: "Are you reminding me that I am old every two weeks?" CN1 continued: by the end they value a lot our contact, in many cases those 10 to 15 minutes are the only contact they have in a space of 15 days. To them, it makes all the difference."

On another hand, CN1 also describes a significant group of active older adults (including people between 90 and 100 years old) who work, go to the gym, travel and have an independent life: "In this group we apply a more preventive approach, promoting healthy habits. Our goal here is to act in advance and detect critical events that they usually do not give attention to, e.g., chest pain. We have forwarded some of these to emergency dispatch. On a subsequent contact they thank us because they were underestimating their symptoms and said that we have saved their lives."

5.5.1.3. Potential users of the online channel

In order to explore the creation of the web channel, we choose to work with group B (seniors with higher literacy levels who are familiar with technology) for the reasons previously explained.

Seniors: All participants mentioned they used the computer every day. Men used the computer to work, check the news, access bank accounts, check email or Facebook, but not as often as women. S6 mentioned: "I use Facebook but I'm not a slave of it". Women acknowledged they were very interested in using Facebook and Skype to talk with their children on a daily basis. Interestingly, only women also reported they like to play games in the computer. S5: "I play a lot of card games, especially when I am more anxious or depressed, it helps me to relax." Consensually, all participants searched the Internet for healthcare topics. One of the other women, showed a high level of computer use expertise, using the computer to search several topics and curiosities:

> *"I like to know about treatments and healthy habits. I check train schedules and book flights and hotels, all through the Internet."*

5.5.1.4. What has been the phone-line experience

Nurses: Depending on the CN, phone-calls with initial evaluations have an average of 5 min but they can last up to 15 min. If it is a follow-up phone-call, durations can be completely different because some people have the need to talk for longer periods.

All participants shared their difficulties about the interaction with the seniors during the phone-calls. CN1 focused her concern on hearing loss problems that many seniors face, which can be a hurdle during the phone-call assessments. She mentioned in this situation, the need for talking loud and slowly (the call can last

20m instead of 5).

In what concerns how the seniors perceive the program, all CNs reported that they have very positive feedback. On a scale of (1-5) where 1 is less motivated and 5 most motivated, 2 of the CN gave 4 and the other 2 gave 5. CN1 commented:

"We have a very positive feedback, mostly from the ones who are isolated. They recommend us to their friends."

CN2 asserted that women like it more than men, who usually tend to say they do not need any help. According to the participants, program dropouts are residual. The main reasons are natural causes (deceased), the fact that the younger participants do not see the need to continue and others think the program is not adapted to them. Most of the seniors follow the programs' recommendations, report improvements (mobility, life habits changes) and negotiate with CNs new goals. However, many say they forget recommendations. Furthermore, as the CNs follow-up is performed randomly, they do not have a way of validating if the recommendations are being followed. Finally, the most reported needs of the seniors to the CNs include the need for contact (CN1 suggested more periodical calls to the ones who are lonelier); speak with the same communicator (when they recognize their voices they express happiness); having more adapted questions according to their context.

Seniors: All the participants joined the program by a contact call from a CN. They have been followed in average for 4 months. Several mentioned they need to reschedule the contact very often because they are usually busy with their daily affairs. All seniors valued the importance of the program and its impact in the senior community. They mostly highlight the psychological support that the program offers, which they refer to be of major importance to isolated people. S4 commented:

"The impact is mainly psychological. We have a feeling of support that when we need, we have someone to rely on."

When questioned about what would be their preferential contact means, most of them preferred face-to-face contact and three suggested videoconference like Skype. Most of them agree that the recommendations given by the CNs have been useful. When asked about if either they memorised or registered the recommendations, 6 answered they memorised and only one said he used the computer. On a scale of (1-5) to measure what has been their experience in the program, where 1 is less positive and 5 very positive, 71,4% scored 5.

Program manager: When asked about what can be improved in the program's current performance, the manager expressed concerns about integrated care, inter-communication of services and healthcare information handoffs between the program and primary health care centres:

"We have people that at the 7th call, start asking: what if an appointment needs to be scheduled, isn't that possible? Also, if someone is needed to come to our home, isn't that possible as well?"

5.5.1.5. Moving towards personalised care

Nurses: When asked about the experience of applying the health assessment MAB tool over the phone, all participants reported the need to adapt the language according to the social-economic and educational status of the senior. They all try to simplify the questions and make a conversation instead of a survey. CN1 said: "We keep restructuring our language and questions according to the feedback we get from the person while we complete the survey". CN4 expressed concerns about the tool, stating that it is very standardised. According to the participant, the tool does not apply equally well to people from group B: "We should not try to standardise and instead get to know the person. I try to adapt the questions to their context. One woman with 81 years old took me wrong when I questioned her if she could count soup letters. She was actually very independent, helped the others and even had a tablet and used the Internet. There should be more flexibility in the questions and in other ways of evaluating cognition."

CN2 and CN4 showed agreement with the concern of calling randomly to seniors without previously knowing their profile and history. Both suggest that it should be always the same communicator calling the senior, having the concept of "family nurse". CN4 explains: "We need more information about the person like its literacy level and the way they like to be addressed."

Seniors: Although the majority of the seniors find the phone conversations with the CNs pleasant, pointing out their sympathy, many of them asserted that the questions are very standardised, not matching their problems:

"S3: The people who contact us only follow the guidelines. Some recommendations don't make much sense and are theoretical. For example, there are many people who do not have any friends or just can't go to a cinema or theatre. There is a gap between the question and the real knowledge of the person who is calling.

S7: People who contacted me do not seem to know my profile and situation as they ask the same questions several times. It doesn't make much sense as we could get into other issues and we lose time with the repetition."

S3 also suggested that the program should differentiate seniors into different groups according to their literacy level to adapt the questions to the person's profile. The majority of the participants prefer to be contacted by the same CN. As they describe, the same person can have more knowledge about their profile and evolution, also helping to create empathy.

5.5.1.6. Enabling provider's data to the seniors

Nurses: All participants showed agreement about the possible benefits that a complementary web channel could bring. Two CNs suggested system functionalities that could bring useful data to them, also engaging seniors in managing their health: "It would be beneficial for the seniors to access their results and recommendations; monitor health habits and weight, e.g., for the diabetics; have system reminders; have a chat when in doubt and provide health education with reliable material."

> *"On a next call assessment we could try to understand through the system if the senior has applied the recommendations. Our starting point would be different. We could also understand if the evaluations and recommendations are being meaningful to them."*

Seniors: Every senior wishes to have access to the results and recommendations online in a secure way. One participant alerted that despite being of great utility, listening to the recommendations does not mean he would memorise or practice it. Another participant highlighted the benefits:

> *"When visualising the information that the person collected, I can interact, acquire knowledge and eventually correct the notes that the nurse wrote about our conversation."*

5.5.1.7. Enabling self-assessments to the seniors

Nurses: When asked about if it could be relevant for the seniors to be able to perform self-assessments, the majority of CNs did not find it very useful, only if they could further validate it on a subsequent call. Despite that, some of the seniors may prefer the online channel to answer the assessment in a more private way. The majority of CNs argues that, currently, seniors seem happy with the phone calls, which is already a way of not feeling so exposed to sensitive questions.

Physicians: When asked if the online channel could be a more reserved way for seniors to answer the assessment questions, P1 agrees with the majority of CNs, explaining that one of the reasons for the phone call channel to exist is to maintain an active conversation with the seniors. The voice is important to understand if the person is well and to comfort seniors, knowing that there is a person on the other side that is willing to help. However, the web channel can complement and improve the calls if we can find ways of engaging seniors into the platform:

> *"For example, we can motivate the senior to value what the nurses recommends during calls or enable cognitive activity tools that can improve memory through games."*

On the other hand, P2 said the web can be a better way to answer some more private questions.

Seniors: When questioned about if they were able to make self-reporting of their evaluations through the Internet all participants answered yes. When questioned about if self-reporting could be a more comfortable way to answer the evaluation, all participants but one answered yes. The most mentioned reason was flexibility. As S2 mentioned: "I do not feel comfortable using the phone because I do not know who the other person is. I would prefer the Internet also because in this way I could have more time to think about the answers."

Despite answering that he would not mind to perform the assessment online, S7 preferred face-to-face meetings. The other two participants both highlighted that the online self-reporting could definitely be a good idea to convince their wives to join the program.

5.5.1.8. The role of family participation: concerns on perception

Nurses: Several participants mentioned that an online channel could be valuable for family members. However, reporting health data in the system, on behalf of the senior might not be a good idea as CN1 explains:

"Sometimes the answers of the seniors are different from their relatives. Their perception is different from one another. The senior may emphasise the symptoms, while their relatives tell a different story."

Physicians: Both physicians agree that it is preferable to be the seniors themselves to perform the proposed online self-assessments. P1 expressed concerns about the quality of the reported data, stating that the seniors should be the only ones to provide it: "If it is the person himself, the evaluation is more focused on their needs and in what the person wishes to communicate…with another person we can lose the specificity of information."

P2 says that if the individual is not able to perform it, a family member could answer on their behalf even if the reported data may suffer from bias. According to the physician, seniors can also benefit from this tool without using it themselves. However, P2 mentions the same as CN1: "Because of their lack of autonomy, they may not have the correct perception of their status."

Seniors: We also asked seniors if they would like their family to have access to their evaluation results. Only three of them would like to share their results with their family, like S7 who explains: "Speaking on behalf of the senior community, it would be convenient having someone that could follow and be aware of the person evolution. It is of total convenience that family members have knowledge." On the other side, S2 expressed her feeling like:

"I don't think it is of much value. Sometimes I wonder if my family is like Google, they only 'search me' when they need."

5.5.1.9. The web as a continuous follow-up channel

Nurses: We evaluated with participants ways of engaging seniors with the new channel. CN2 suggested: "We can try to understand who uses the computer during our phone-calls, if they have access to the Internet or if their children would use it for them. Currently, many of them are receptive to new technologies like tablets." CN4 suggested the idea of presenting the opportunity to seniors of giving online feedback after the phone conversations. A very important reason for adoption would be for people who have severe hear loss problems.

Physicians: According to the participants, the online channel has the ability to enrich patient knowledge, through the collection of health data by the seniors between the phone-calls. This data should be related to the treatment and be self-collected by the senior as a way to improve the quality of the phone calls follow-up. P1 suggested:

> *"The online channel can complement the phone channel as a tool that monitors events of the senior's daily living that usually people don't recall during the calls, mainly at the emotional level."*

As a suggestion for the channel engagement, P1 mentions that it is necessary to give time for seniors to interact with the new channel so the program can understand their behaviour and create motivational reminders and messages according to their profile and interaction patterns. In a similar way as CN4 previously mentioned, the online channel could be a way to include people with hearing loss. P2 reinforces this issue by thinking on the potential of involving this target group through the web: "In this case we would act with a different kind of follow-up care: firstly, the channel could screen the person's profile, providing personalised online material like advisements according to the individual needs, having the potential of forwarding them to other services of the NHS. This way we could start including this target senior group in our program."

P2 presents two ways of promoting channel awareness among the seniors: (1) From the phone to the web: after the first contact, CNs can mention seniors that educational material can be provided to them online; (2) from the web to the phone: promote the program so people can get to know the service and join the phone calls follow-up.

Seniors: All participants showed interest on interacting with a web channel in a complementary way to the program. One of them highlighted:

> *"One thing does not replace the other. Both can complement each other, the web can offer a continuous follow-up, for example, receiving material in our online personal area, when the nurses are not able to call us on a certain day."*

Program Manager: For the manager, the possibility of creating a platform where senior people can reflect and know more about their healthcare status is a channel for promoting awareness to the program. The most highlighted benefit is the possibility of seniors sharing their data with healthcare professionals. The participant showed interest on connecting wearable and sensor devices with the web channel: "Our program wishes to evolve to healthcare monitoring procedures in life risk situations of the seniors, e.g., monitor a chronic disease like diabetes, fall events or high blood pressure, so we can act immediately."

5.5.1.10. How can both channels (phone and web) be integrated

Physicians: Both physicians explained that a validation of the service would be required after the senior performed self-evaluation. P1 suggests how both channels could be integrated: "This open access of the initial assessment could attract people to the program by giving the opportunity for seniors to answer the question, how is my condition?" According to their self-assessment results, they could register online, by sending a message that would trigger an alert into our service to contact them. A further validation by the CNs would be required on an initial conversation to include the person in the program.

After the initial assessment validation, the subsequent follow-up calls that are usually scheduled with the seniors according to their preferences, could then be enabled in the senior's online personal area, sending alerts to them by the time of the phone meeting, as suggested by P2. Both of the participants asserted that only the initial evaluation should be enabled in the online channel. The subsequent follow up evaluations (different questionnaires that depend on specific health domains, according to the initial evaluation results) should be limited to the phone calls. Furthermore, they suggest that people could be notified by the time for reevaluation.

Program manager: According to the manager, a bridge can be created between channels. The ideal integration between the two channels would be the ability to search for a certain topic and advise the person to clarify its needs, together with a healthcare professional.

5.5.1.11. Displaying ICP results to the seniors

Physicians: Both physicians see benefits of displaying the ICP results to the seniors. P1 describes that, from a qualitative perspective, the senior should be able to perceive to which health domains they are more vulnerable to and could be improved. Associated to that qualification, a simple diagnosis should be provided. The recommendations should be associated with an option for seniors to report if they can put them in practice. For P2, accessing the data about their records and seeing that their answers had a visual feedback can be very helpful:

> *"This way there is a quick feedback about their integrated healthcare evaluation. The seniors would understand what would be their strengths and weaknesses and the next scheduled phone calls for the follow-up."*

Nurses: The majority of CNs expressed concerns about giving seniors access to the ICPs. CN2 alerts:

> *"We should be careful. The data results should be presented with care and adapted to the seniors."*

CN3 commented that it should be possible to select which visible data should be displayed in the ICP like the notes they write about the seniors, while CN4 suggests that the online view of the ICP by the senior could reinforce their positive side. Motivational messages should be given to the seniors according to their most positive evaluation results.

Program manager: The participant also alerts to sensitive information when it comes to present the results of the ICPs. If a given score in a health domain is very critical, a system message should alert a CN to call, instead of presenting it to the senior.

5.5.1.12. Identifying which PHR tools can better support seniors

By the end of the interviews, we focused on evaluating both seniors and providers (nurses and physicians) perspectives of what the web channel, in the case an integrated PHR, should include. We firstly studied the possibility of associating educational material, to the ICPs. Secondly, we analysed which health behaviour data collection tools could complement them, enabling more knowledge to all the different profiles. The set of feature options in both categories were defined according to the extensive literature review available in Section 2.8; the relevancy to this use case; and previous research findings that show the adoption of PHR tools by seniors [40] [106].

The answers between the several groups can be compared in Figure 37 and Figure 38. When seniors were asked if they wished to have access to educational material, provided by the program, all answered yes.

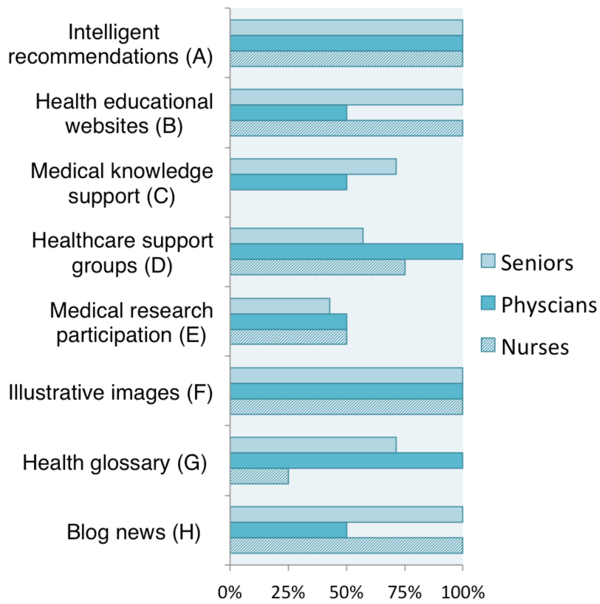


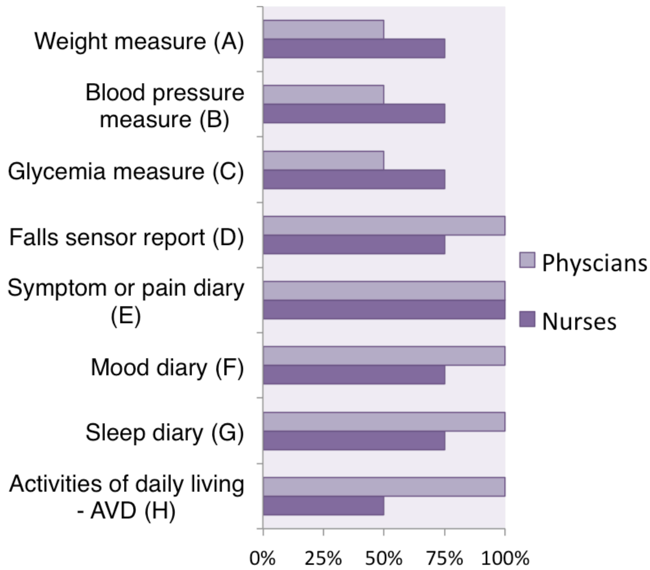
Figure 37: Preferential educational material for the nurses, physicians and seniors.

All seniors stated they already performed online searches on healthcare topics and valued the possibility of having access to trustworthy material. The most desired features for all the senior participants regarding the educational material (see Figure 37) were (A), (B), (F) and (H). Four seniors highlighted (C) as one of the most wanted features, which is controversial with the nurses and one of the physicians who showed concerns on the senior's access to clinical terms. Some participants also showed interest in the feature (E), as S6 mentioned: "My wife would like to participate in medical research because she had a cancer…she has already asked me how she could participate". Moreover, S7 also mentioned that the proposed material content should be enabled according to the capabilities of each senior. The most wanted features both for nurses and physicians were (A) and (F). Participants from all the groups showed consensus in (A) and (F).

For the nurses, feature (A) could work as "a reinforcement" of the recommendations given to seniors, during the calls. In (B) both nurses and physicians reported that the access to credible information might be very useful to the seniors. CN2 commented,

"They search a lot in the Internet but the information is not the most accurate and sometimes they get frightened."

P1 alerts: "We should enable content only created by the NHS or by a certified entity." CN3 also valued feature (D), mainly for diabetic people. In what concerns the preferential behaviour and health data collection tools that the integrated PHR could have, we did not get into great detail with the senior group. We mostly wanted to know about their interest in self-monitoring, so the healthcare providers of the program could have more information over time. They all showed interest, except for one.



38: Preferential self-tracking tools for nurses and physicians.

In Figure 38, we can compare the preferences of nurses and physicians regarding the self-tracking PHR tools. The most consensual was feature (E): all participants showed most interest in the symptom diary. CN3 explained, "It can help to identify a health problem prematurely through reported symptoms like chest pain, difficulty in breathing or fatigue". CN4 also suggested the system to ask periodically:

"How do you feel today?"

CN1 and CN2 also commented the importance of biometric measurements, features (A), (B), (C) and fall detection (D), mainly to people with chronic problems like hypertensive or diabetic people. Nurses find these tools very useful also as a way of forwarding to other NHS services in case of emergency.

Finally, we asked physicians and nurses to think if enabling online self-assessment could support other types of answer editing that could not be performed over the phone and could be an asset to the comprehensive assessment. All the participants from both groups saw the opportunity of having a more detailed evaluation through the web. The most frequent suggestion was the ability to test the cognitive status of the individual, through visual exercises or cognitive scales that could test, for example, memory or hearing. P1 also explained:

> *"We could include images and calculations. We had to use sub-optimal cognition scales because of the phone. Here it could be possible to use more robust scales."*

5.5.1.13. Discussion

This study presented the perspectives of the different stakeholders of the Portuguese Nationwide Senior Telehealth program with the aim of evolving the experience to a cross-channel platform (combining phone and web). A qualitative analysis of interviews conducted with seniors, nurses, physicians and the manager of the program, supported the identification of the major issues in the current service, and the more promising paths towards the envisioned integration.

Both nurses and seniors expressed that currently the service calls were very standardised, requiring an adaptation of language and discourse. Some nurses highlighted the importance of restructuring the questions in order to provide a conversation instead of a survey, whilst seniors asked for a more personalised evaluation of their condition. Both groups mentioned they would prefer to always contact with the same person, as prior knowledge can benefit the interaction and patient-provider relationship. The group of nurses who were in the program for a longer time, felt this particular need.

Among the findings, the complementary nature of the phone and web offerings must be highlighted. While the phone channel promotes an active voice with the seniors, important to avoid loneliness, the web can enrich patient knowledge to providers and engage seniors in the program through a continuous follow-up care model with the ability to track events of the daily living of the senior that usually people do not recall during the calls.

Furthermore, the web can extend accessibility to those who are prevented from attending calls due to severe hear loss disability and inform providers on how seniors are addressing recommendations. Challenges arise when considering the validity of self-reported data and the privacy concerns that emerge in Internet data exchanges. Whilst seniors showed interest on performing online self-assessment, one of the physicians alerted to the need of supervision in the recorded data. Furthermore, both nurses and physicians questioned the role of family participation in reporting data in the PHR, as their perception may highly contrast from the self-awareness of the senior, especially in depressive clinical situations. This reluctance, both from doctors and care personnel, has also been highlighted in previous studies revealing that telehealth monitoring can include not only a higher probability of false alarms, but also data security issues [225].

All seniors wished to visualize and interact with their individual care plans over the web. However, whilst physicians suggested that visual feedback about their holistic assessments could be very useful for them, the nurses and the program manager advised that the data should be carefully displayed, only reinforcing the positive side.

5.5.2. Generative and field research

Aside the interviews qualitative study, observation and generative methods also took part of this investigation. Field research study was conducted in LCS facilities, applying ethnographic methods to gather information about the service work process of the program and also participatory design methods that involved the physicians and nursing staff in the design model proposal of the "H24 Senior app".

5.5.2.1. Contextual inquiries

We visited several times the workplace of the Portuguese Telehealth Senior program, interacting with several nurses, the two physicians from the clinical concept team, the program manager and the staff from the help desk. Our goal was to collect information about the work processes and how the Nationwide program was built and managed, which was achieved through several contextual inquiries conducted with both groups. We had freedom to observe how the nurses performed their calls to the seniors enrolled in the program and how the MAB assessment tool was adapted by the physicians to be used in a telehealth environment. One hard task that was done, was to lessen the number of questions from the tool, keeping the most benefit of its original structure and to convert it to a software algorithm. Several versions were constantly being updated over time to improve the algorithm, with the goal of affecting positively the performance of the follow up care provided to the seniors and their final healthcare outcomes. This conversion was carried mostly by one of the physicians (P2) that worked closely with the responsible of the software development team.

One of the contextual inquiries was performed with one of the nurses who was asked to present a software demo to us, explaining step by step, their work method of assessing the seniors through the phone calls provided by the service. According to this inquiry, the current software was accessed through the web and was considered to have low speed and provide limited functionalities to the nursing communicators staff.

When nurses start following a senior participant for the first time, they conduct an initial Global Health Assessment (GHA) through the phone, recording the answers through an online form of the system. By the end, an Individual Care Plan (ICP) is automatically displayed, which shows the results through a visual diagram and a summary with highlights of the person overall status, identifying frailties and selecting an appropriate set of recommendations, when necessary.

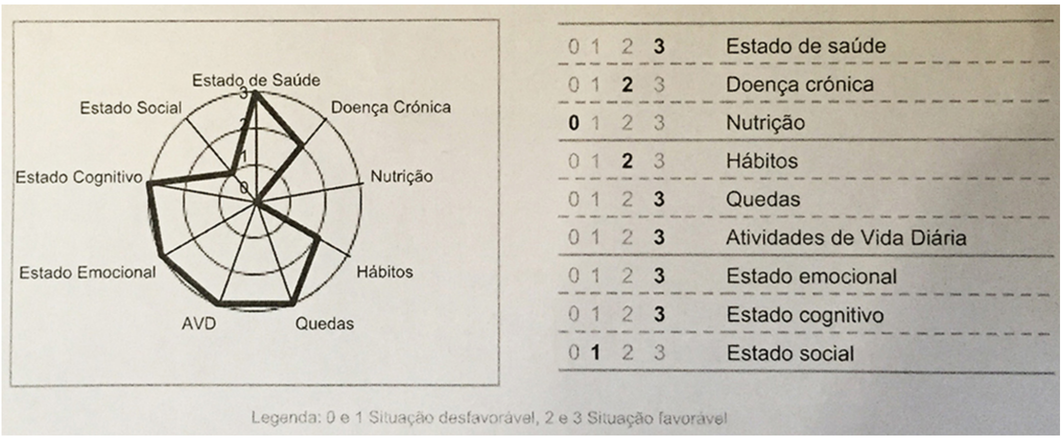


Figure 39: Paper version of the results of an Individual Care Plan, displayed through a polygonal diagram to the nurses.

In Figure 39, we can see an example of the diagram in paper version (for privacy reasons we were not able to collect pictures of the system) that is displayed on the screen to the nurses after the results are generated. The ICP also presents the subsequent assessments that should be performed by the nurses in the following calls according to the plan, which become scheduled in the system. As an example, according to the ICP results, a senior person can be followed within a period of 3 months, with fortnightly calls, in the dimensions of nutrition, emotion and cognition (this is a random period of time that depends on the nature of the assessments and follow up periodicity determined by the program). After this care plan is accomplished, another GHA is repeated to reassess the person's condition. Again, a new ICP is generated with a new set of follow up calls for a next timeframe. As aging is a natural process, providers do not expect the person to recover from chronic conditions but instead expect helping maintaining their autonomy by providing recommendations that can improve aspects of their condition or prevent them to worsen.

Whilst the first call needs to be initiated by the senior because of the service model, the subsequent calls are initiated by the nurses. Every time a nurse begins their shift, they begin by opening the software program and visualise the group of seniors they need to call to, in that day. When they start calling, some seniors often either do not attend the call or reschedule for another day. Phone calls are performed randomly to the seniors. By this means, there is no allocated nurse to the person that is being followed.

Major concerns that were reported (also during the interviews), is that the system works basically with the assessments report and calls scheduling functionalities but does not have a way, for example, to access the person's history and compare how the person is evolving over time, in each macro and micro dimension of the MAB assessment tool. The recommendations of the ICPs displayed in the system, also presents nurses too many options to be given to a senior during a call (the call should last approximately 15 minutes), which requires the nurse to select only about three, according to their preference, which in some cases can cause confusion.

Moreover, the information about the senior is limited to their name, age, NHS identifier number and home address. The system does not provide a way to record their socio-economic status, family support, special needs (e.g, prosthesis), home conditions and the way that seniors would like to be treated during the calls. This was a highly discussed point during the interviews, which was seen as a blocking issue to a have a user-friendly, personalised program. As an example, as assessments are too generic to be applied to a wide spectrum of people, recommendations may fail if there is unawareness about the particular context of the person. If a nurse suggests the person to go for a daily 30 minutes walk and does not know that the senior has a leg prothesis, this recommendation may be out of purpose. Moreover, nurses did not have a way to report in the system if seniors could either put recommendations into practice or not. Adding the fact that the calls are performed randomly to each senior and that nurses begin the calls without any prior knowledge about the person, communication issues arise, making the seniors repeat themselves every time they receive a new call and also making harder, the work of the nurses. Besides the lack of a "history profile" and "handoff" features in the system to be accessed by the nurses before the beginning of the follow up calls, nurses have also shared their hurdles in not having an integrated system. In case they need to know which medication the person is taking or what are their healthcare history events (for example, to know if the person had a recent emergency episode that required hospitalisation and is now recovering at home), nurses need to switch between other systems, which they have reported to interfer with the performance of the calls and quality of attendance provided to the seniors.

5.5.2.2. Participatory design sessions

The user interface design of 'H24 Senior app' was based on a functional analysis that derived from the qualitative interviews and contextual inquiries findings. After these previous methods were conducted, the UI was also a result of an interactive design cycle process, where participatory design methods were applied in collaboration with a clinical team. Two nurses (communicators) where selected to work with us, along with the two physicians from the conceptual team. Moreover, we also involved at this stage the author of the MAB tool (external to the program).

First, the functional analysis was validated by the responsible physician of the clinical concept team (P1) through a checklist that described each feature, by checking if she agreed or not with each one. Features were grouped within the several areas of the system information architecture and had corresponding requirements and quotes from the interviews that also helped to justify them. The reviewer was asked to define, using a 5-point scale, its relevancy and implementation priority level for the program. The checklist also associated comments and suggestions field that was filled with several inputs from the reviewer, which helped us to better frame the requirements.

As an example, P1 suggested that the ICP should be displayed to seniors in an attractive way and list recommendations with a clickable component, so the user could report if they were able to put each recommendation into practice or not. P1 added: "the web-channel has the ability to provide an alignment between what is desirable and what is possible". This is because currently, recommendations are reported in a very standardised way to seniors during the phone calls and there is a gap for a more personalised care.

Whilst nurses try to do their job as best as they can, they do not have a way of knowing if seniors are able to put recommendations into practice, according to their context, which interferes with the expected outcomes of the care plan (also reported in the contextual inquiries). This example shows the approach we encouraged the clinical team to have during the collaborative work and participatory design as it stands for the benefits that combining both channels (phone and web) could bring.

Autonomy	Health	Social
Falls	Cognition	Habits
Activities	Emotion	Social Interaction
	Complaints	
	Nutrition	

Table 3: Macrodimensions and microdimensions of the Global Health Assessment.

Moreover, both physicians from the conceptual team were involved in the definition of user flows, exploring the registration process and the service first contact (that can also be applied in subsequent contacts). The goal was to explore together with the clinical team, how both channels (phone and web) could be integrated in the service, providing a more complete cross-channel experience, also by including people with hear loss. These user flows are described later in this thesis, Section 5.6.2.

After having the functional analysis approved, we were able to design a user interface (UI) proposal for the application which was also validated through participatory design sessions, held with the clinical team in individual sessions. We applied paper prototyping to validate the UI of the design model proposal, presented to the program reviewers as page layouts, simulating the screens workflow. We wanted to understand if the data and features that senior users were going to interact with, were relevant to the clinical staff. Suggestions for changes were made using post-it notes as screens were being displayed during the session. The feedback left by the reviewers was very positive, and the proposed changes were mostly related to the information architecture terminology, organisation and the contents (see Figure 40).

An individual participatory design session was also conducted with the original author of MAB, Prof. Dra Maria Amália Silveira Botelho. The goal of this session was to discuss and adapt the tool into a self-assessment perspective, to be used by the seniors. The reason for designing the tool according to the author of MAB was because we wanted the web channel to go beyond the limitations of the phone line, keeping its original framework. As a result, the 3 macro and corresponding 9 microdimensions of the Global Health Assessment that we adapted to the self-questionnaire in the "H24 Senior app', can be found in Table 3. The final MAB self-assessment structure of questions, can be found in Appendix F.

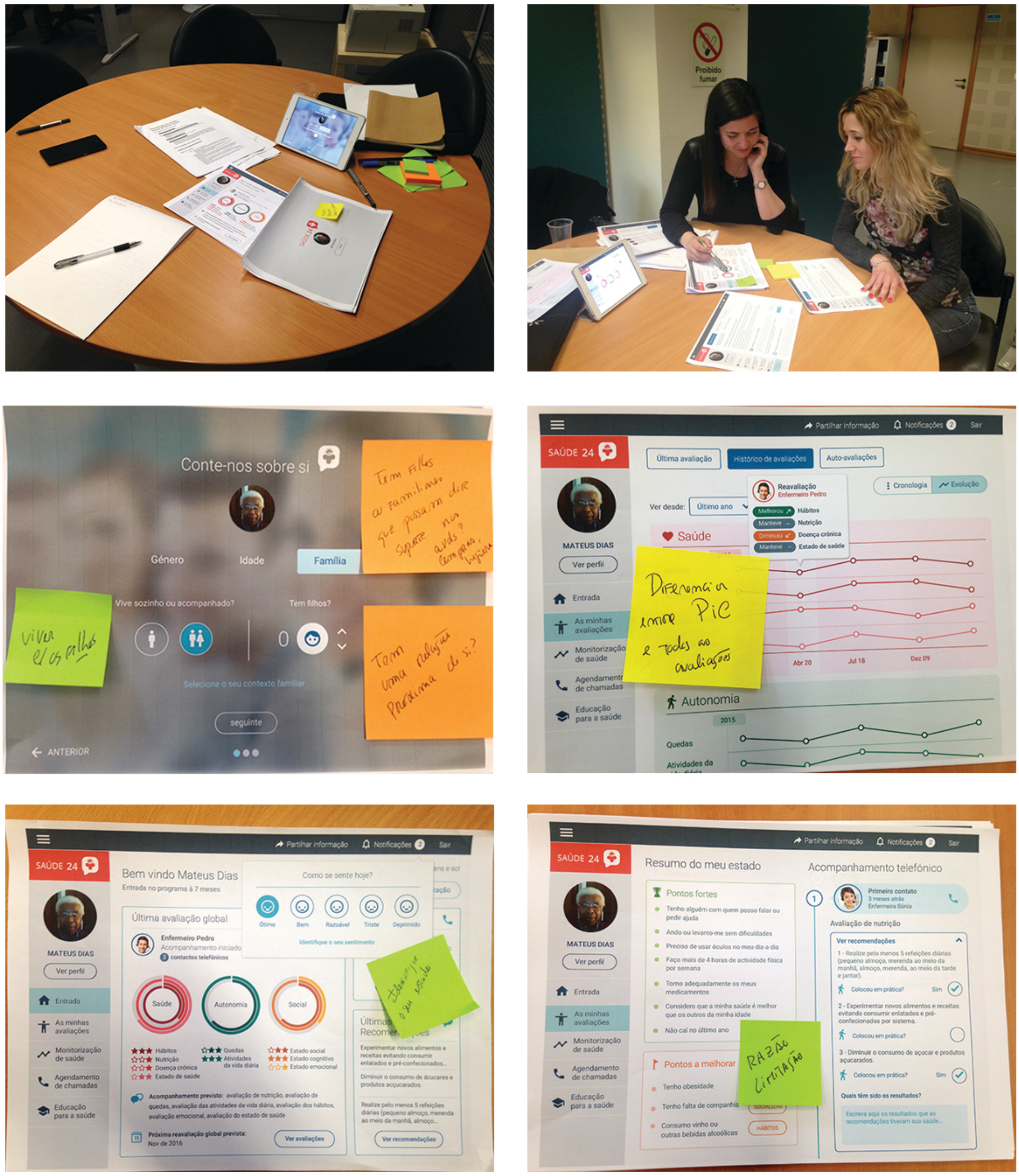


Figure 40: Participatory design sessions with the nurses and physicians.

5.6. Design Model Proposal

The design model proposal for the development of "H24 Senior app" was sustained on a functional analysis that derived from the user research findings of this use case and was also based on the previous extensive literature review of this thesis. The functional anaylsis specifications can be found in Appendix J.6. The functionalities that were selected from the review are checked in the Integrated PHR features collection, Section 2.8. This chapter contemplates the application structure, user flow diagrams and the user interface design (UI). In this use case, the UI was designed in an agile way by creating a set of mockups with visual design as a template, which was being implemented and improved until the final version was implemented. The user flow diagrams were necessary in this use case to (1) demonstrate how the channels of phone and web could be integrated in the service to engage the senior target users to register in the program, also showing solution for the first contact, after the registration is complete, and (2) demonstrate the potential of the online channel and the Integrated PHR model.

5.6.1. Application Structure

This section represents the main structure of the "H24 Senior app" in a diagram with two navigation levels.

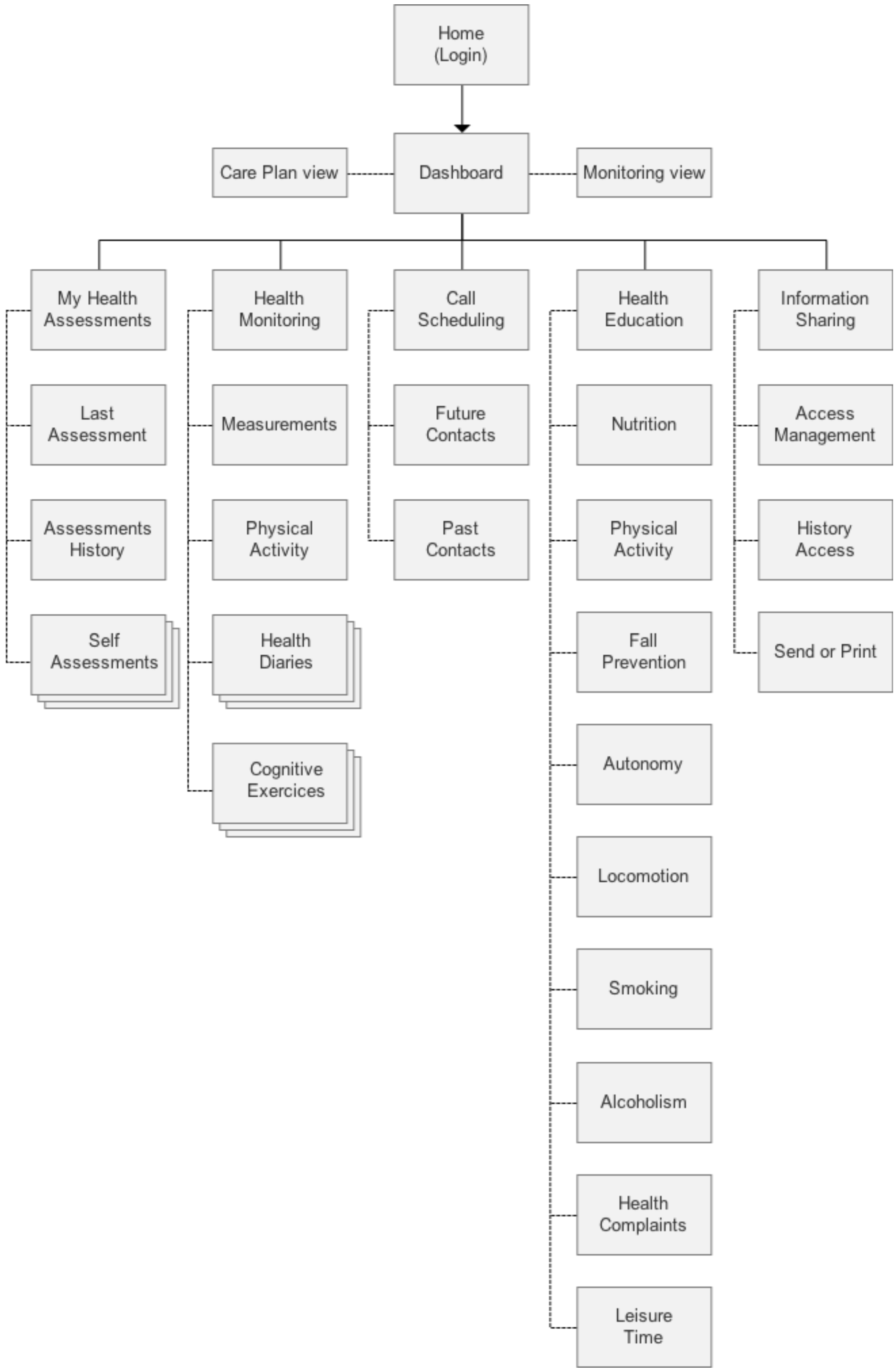


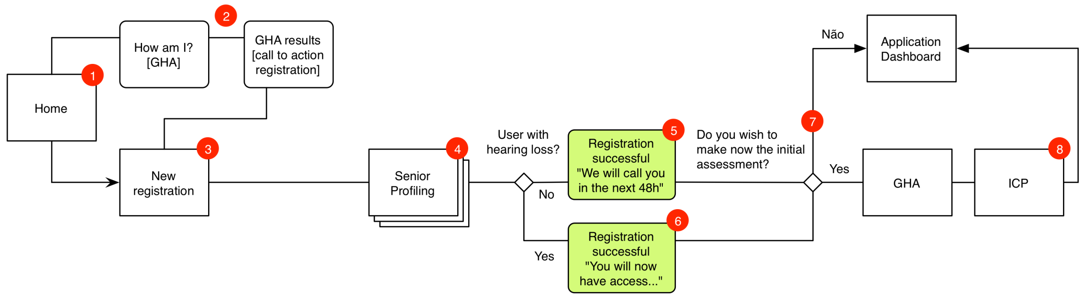
Figure 41: Proposal for the application information structure of the web channel 'H24 Senior app'

5.6.2. User Flow diagrams

The study of this use case includes two user flow diagrams that represent possible strategies (derived from the stage of user research) that show how both channels (phone and web) can be integrated in the registration process and in the contacts performed by the service (first and subsequent).

5.6.2.1. Registration process

The registration process user flow (see Figure 42) gives the user the alternative of either answering the initial Global Health Assessment (GHA) at the website, before (to first become aware of their wellness state as an engaging strategy) or after they decide to join the program or just leave it for the first contact that will be performed later by the nurse, during the first call.



1 Homepage of a website for the H24 Senior Program:
Briefly explains how the program works and it benefits for the senior wellbeing.

2 A quick question in the homepage "How am I?" allows the user to make the GHA beforehand. The goal is to make the user self-aware of his/her integrated health and by this, stimulate them to register in the program.
In the end of the results, an associated message with a call to action, is displayed.

3 The user can register on their own or in behalf of a family member or a case manager.
During registration, the user is asked about their hearing ability to answer phone calls.

4 Senior Profiling:set up profile wizard divided into 9 steps:

- Photograph
- Gender
- Age
- Family context
- Education level
- Occupation
- Ability to answer the phone
- Way of treatment
- Contact number

5 If the person is able to join the call service, the following message is displayed to the user:
"Your registration has been successful! We will call you in the next 48 hours to begin your follow-up care by one of our Nurses."

6 If the person is not able to join the call service, the following message is displayed to the user:
"Your registration has been successful! You will now have access to professional care advisement through 'H24 Senior online'. You will be asked periodically to answer specific health assessments according to your profile and we will provide you an updated Individual Care Plan throughout the time."

7 In the end of the welcome message, the user is asked if he/she wishes to make the initial GHA of the follow-up care program right away or later:
"Do you wish to make now the initial assessment?
(help us understand your integrated health condition to begin your follow-up care)..."

In case the user has answered beforehand, during the registration process, this step is ignored by entering directly in the application.

8 After answering the initial Global Health Assessment (GHA), an Individual Care Plan (ICP) is displayed to the user. This ICP will vary according to the type of user. If the user has hearing loss or if he / she does not wish to join the call service, the ICP can be more focused on complementary e-Health services or a different type of online advisement.

Figure 42: Registration process flow diagram.

These alternatives aim to stimulate the user to register, considering different interaction design strategies that also trigger the type of user through a user profiling wizard feature. According to the user profile, a new possibility is suggested to the telehealth program by demonstrating that people with hear loss can also be included through a different approach. Despite not being able to answer the calls, this type of users should be able to perform the several assessments that are planned by the program over the phone by receiving notifications periodically, applying the same timeline of the phone calls (or even more periodically, as it would not be restrictive to any constraints of the business phone call model). The access to recommendations and educational material would be provided automatically and the Individual Care Plan (ICP) in this case, could be more focused on complementary eHealth services of the Integrated PHR or on a different type of online advisement. To include these new type of users, a new workflow for this use case study should be further studied to be applied in the system, in future work to this research.

5.6.2.2. Service first contact

The 'first contact' user flow (see Figure 43) demonstrates how the service phone calls can become more personalised, and what type of content can be enabled in the Integrated PHR right after the call is performed with the user.

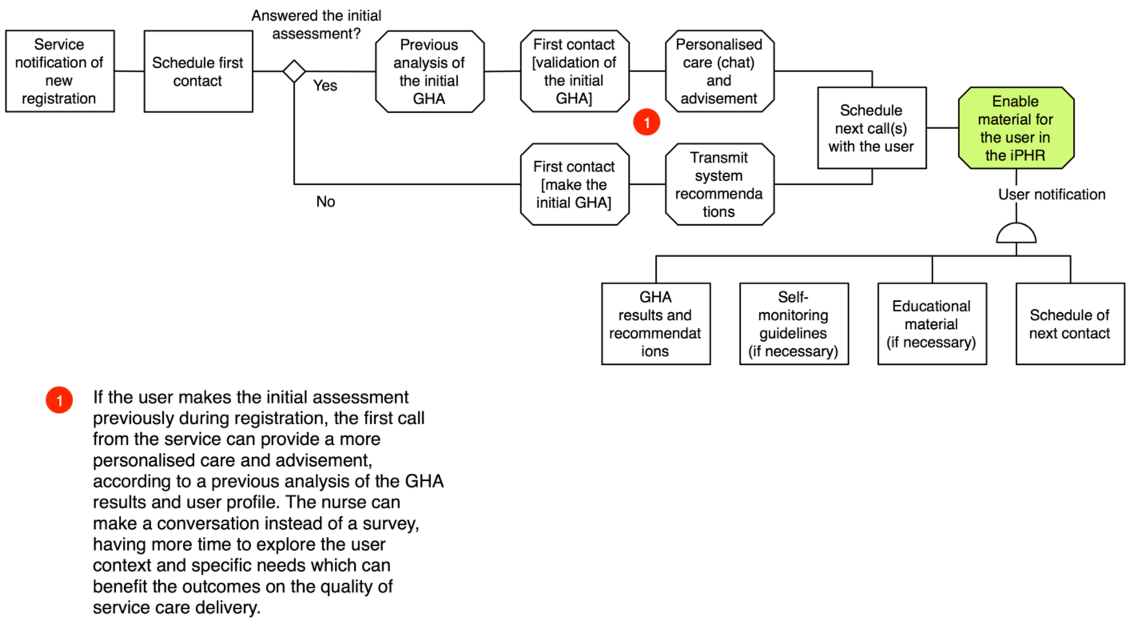


Figure 43: Service first contact flow diagram.

The alternatives given during the registration process can also be designed in a way that the user needs to make the GHA as a mandatory step to register in the program so that on a first contact, a nurse can make a conversation instead of a survey. However, if the GHA is first made by the senior, it always need to be validated by the nurse during the call. Furthermore, this workflow could be applied to every upcoming calls that requires a global reassessment, by notifying previously the user to fill a GHA in the system. This strategy would provide more time for the nurse to explore the context of the user and their needs, which can benefit the outcomes of the quality of the service care delivery. Nevertheless, it is given as an alternative, as some users may not wish to answer the GHA online and just have a quick way to join the service phone channel. The user flow for the service first contact can also be applied to subsequent phone calls.

5.6.3. User Interface Design

The UI describes all the areas that compound the proposal of 'H24 Senior app', which in this use case, displays the final screens from the prototype (print screens from the usability sessions) as they were totally developed and implemented by the engineering master student who collaborated with this research work. Moreover, the UI also includes the design of a complementary app for a smartwatch to be connected with the Integrated PHR, which was also developed by the student.

During the design of the application, we explored diverse visualisation techniques in the UI (e.g., charts, timelines, dashboards) that followed a self-awareness approach by (1) synthesising the user engagement within the program; (2) allowing seniors to reflect about their follow-up assessments; (3) enabling seniors to perform self-assessments; (4) stimulating the collection of self-monitoring data to reflect on the individual wellness behaviour. In (3) we demonstrate how we adapted a method for assessing the bio-psycho-social dimensions of the senior used by the program, into a self-report questionnaire that displays in the end a holistic chart and recommendations to the seniors. The study presents the several stages of an interactive design cycle process, in collaboration with the clinical team.

5.6.3.1. User profile

At the first access to the system the user is shown a registration form, divided into 9 steps (see Figure 44) to build his profile by indicating the personal information. In the first step, the user can upload or take his photograph. In the next three steps, the user is asked about their gender, age (calculated by completing the date of birth) and family context (with questions about whether they live alone or with a companion, how many children they have or if they may count on family support). Afterwards, the user fills the level of education and what was their last profession or occupation. Finally, the last three steps allow the user to set their way of communicating and engaging with the program: First, the user is aked if they are able to attend phone calls or if they have any type of permanent hearing impairment, followed by the way the user prefers to be addressed by the nurses during the calls (e.g., by the last name or title of last profession) and the input of the phone number for answering them.

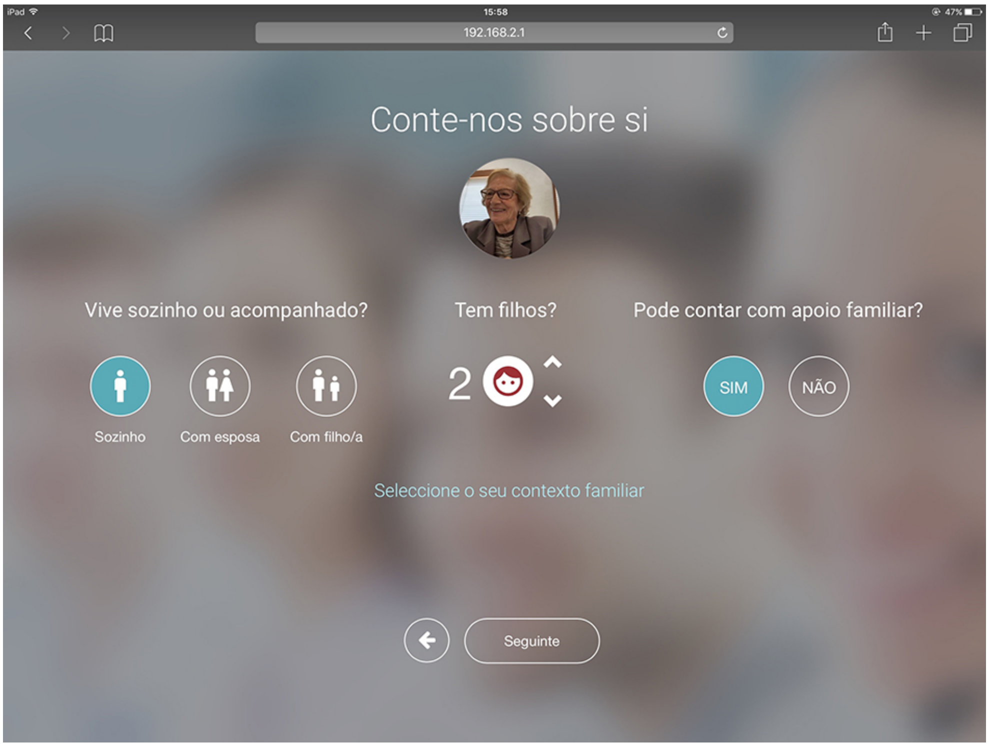


Figure 44: User profile registration form.

The user profile can then be consulted after the login. Besides the basic information from registration, the user can add more detailed information about this profile in the following categories: “Family context”, “Social context”, “Personal contacts”, “Emergency contacts” and “Special needs” (motor incapacity or existence of implants or prostheses).

5.6.3.2. Dashboard

The information available at the dashboard, is divided between two views: “Care Plan” view and “Monitoring view”. The “Care Plan” view (see Figure 45) reflects the interaction with the program and shows in a dashboard, the information about the user last Global Health Assessment (GHA) through a displayed chart (with the results attributed to each of the assessed health micro-domains); the planned subsequent phone call evaluations in the follow-up care plan (e.g., nutrition or falls prevention) derived and associated to that GHA; the expected date for the next GHA.

Figure 45: Dashboard Care Plan view.

This view also presents the date for the next scheduled contact (including the responsible nurse for the contact and the type of assessment that will be done during the contact) and what were the last three primary recommendations from the last contact.

The “Monitoring” view (see Figure 46) displays the summary of biometric data and several features for motivating the users of the program to develop their daily physical capacity. Biometric data includes weight, body mass index (BMI), heart rate and blood pressure. In physical activity, the user can visualise: which activities they have recently practiced; what are their daily or weekly goals negotiated during the calls with the nurses displayed through a ring chart that shows how much they have accomplished to complete their goal in that day (e.g., 20 min daily walking); what is their level of sedentary or active lifestyle, displayed through another ring chart (here a smartwatch would be necessary to automatically measure their movement throughout the day).

Finally, the dashboard also displays an area called 'H24 Senior Records' that encourages the users to "compete" in a positive way amongst them, presenting a list of the participants who achieved their goals that week. The goals are proportional to the capabilities of each senior. They may differ in timings and type of activities in order to have an adequate classification, set with the nurses.

Figure 46: Dashboard Monitoring view.

5.6.3.3. My Health Assessments

"My Health Assessments" is divided into 3 subsections: "Last assessment", "Assessments history" and "Self-assessments".

In "Last assessment" (see Figure 47), the user can access their last global health assessment (GHA), which offers the user two-chart proposals for A/B testing purpose to ascertain the users preference. The GHA comes with the associated undergoing Individual Care Plan (ICP).

Navigating down the page, the results are associated with an item list about the "Summary of my condition" (see Figure 48), divided into "Strengths" and "Points to improve".

Each of the listed improvement points has a link to the "Health Education" section with the corresponding advice from the program. Furthermore, the user can also visualise in the same interface the history of the phone calls through a timeline which is organised by the date of contacts (past and future), showing for each one the name and photograph of the nurse and the type of assessment that was performed (e.g., nutrition).

Figure 47: Chart A (top) and chart B (bottom) of last assessment.

In each contact that has already occurred, the user is given the opportunity to view the recommendations advised by the nurse during a call and is able to answer whether or not they can put them into practice (see Figure 49). Each contact also gives the user the possibility to give feedback about the quality of care in a 5 star scale. Finally, this section also provides a chat area where users can exchange comments with the nurses regarding the results and the ability to share them in future medical appointments.

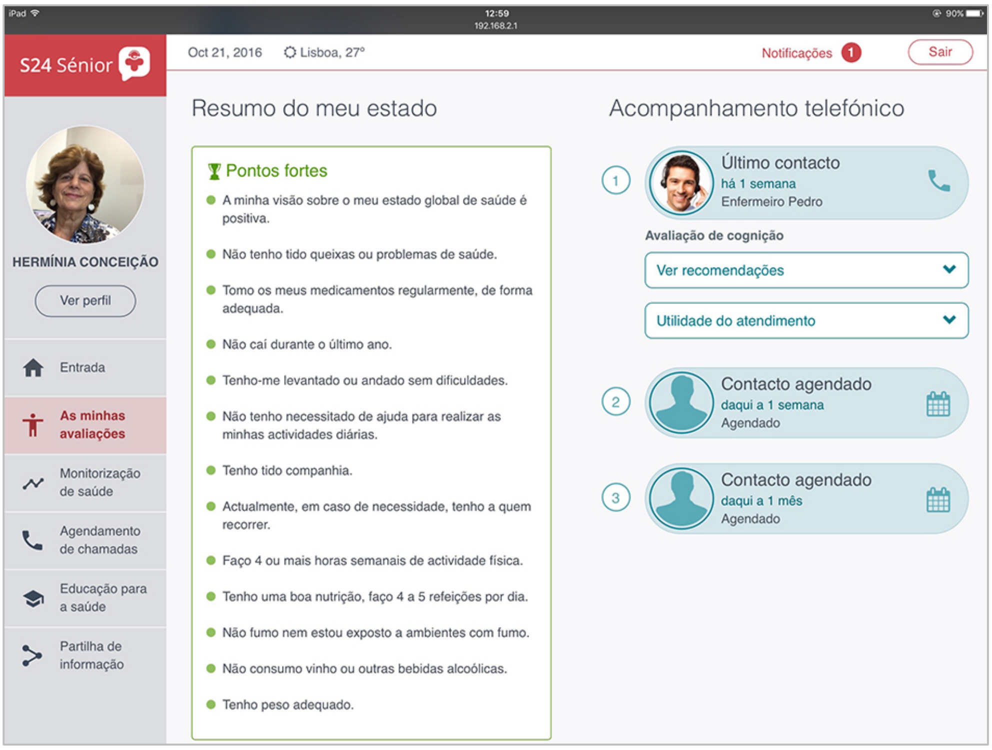


Figure 48: Summary of my condition and phone calls follow up timeline.

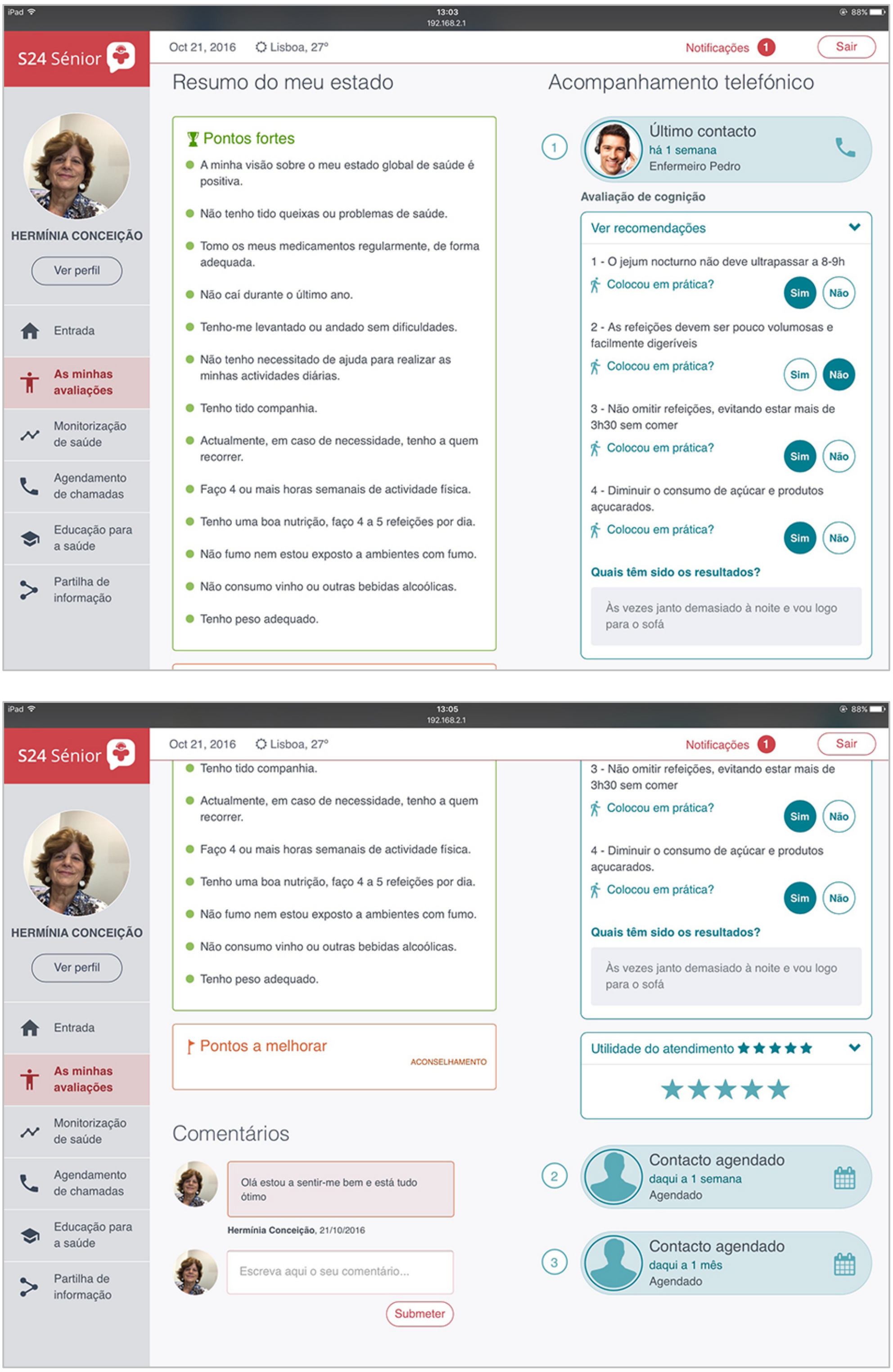


Figure 49: Expanded recommendations and the quality of care evaluation.

The "Assessments history" is divided into the timeline view and chart evolution view. The main goal is to give the users a temporal perception of their health evolution over time, in the program. In the first view (see Figure 50, top), a timeline is displayed with the complete events history and all the assessments made to date.

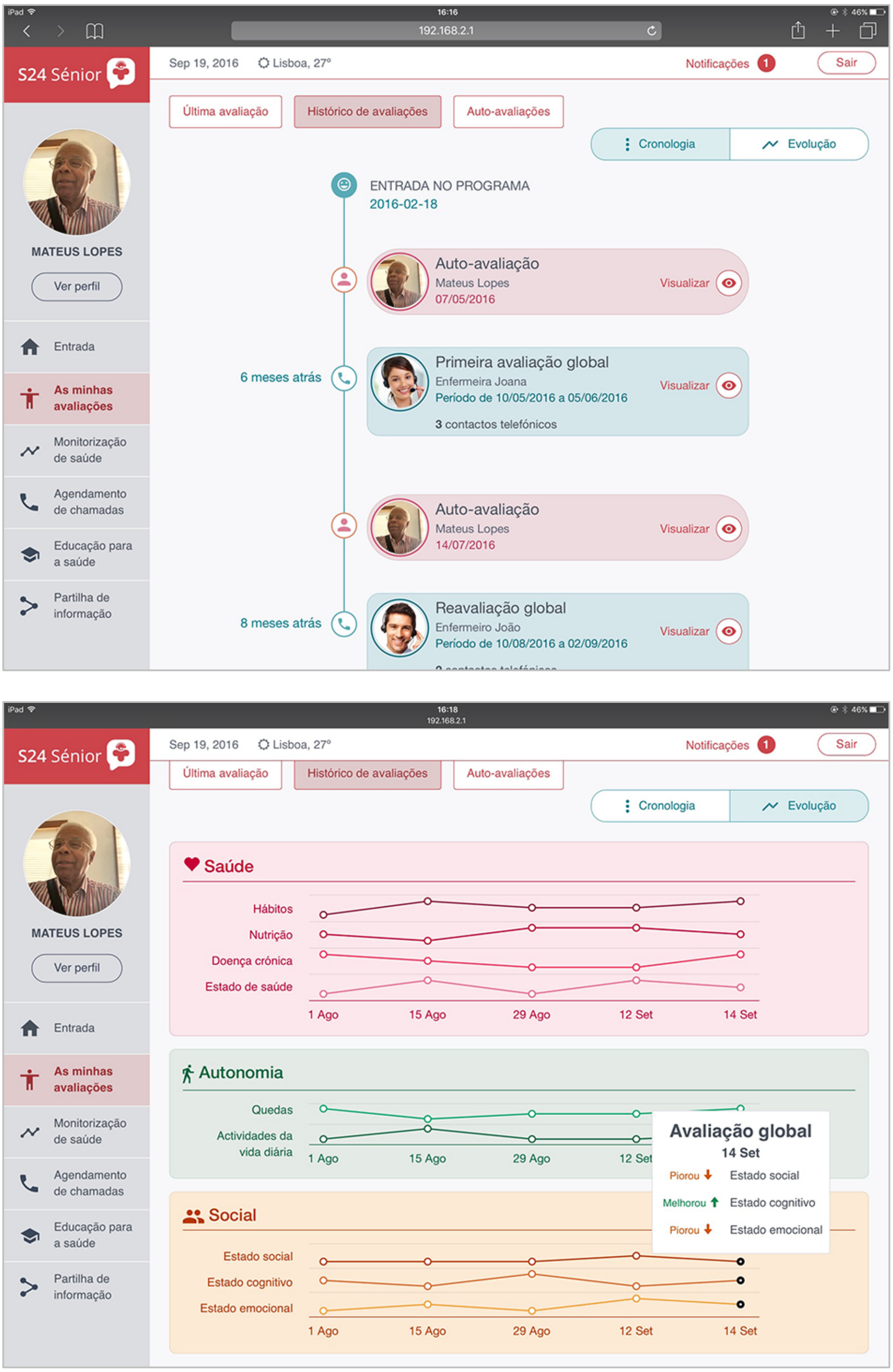


Figure 50: Timeline view (top) and chart evolution view (bottom).

In the second view (see Figure 50, bottom), an evolution chart that gathers all the several GHAs that were made over time, is displayed, showing the user several graph lines for each evaluated microdimension, grouped within the three major health macrodimensions of Health, Social and Autonomy.

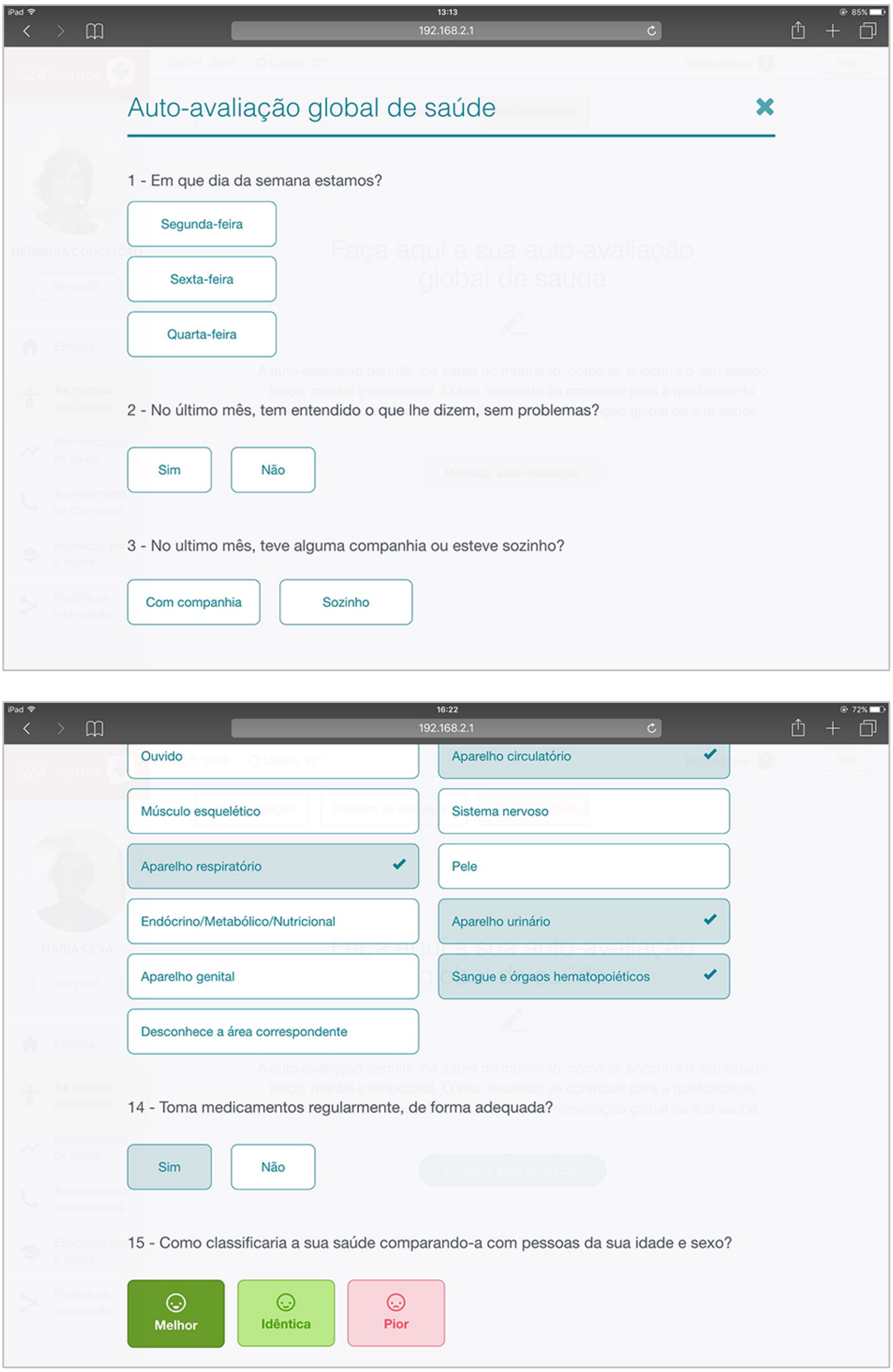


Figure 51: Self-assessment questionnaire.

To make a self-assessment, a questionnaire that applies the adapted MAB tool in this research, presents 22 questions (see Appendix F) in an overlay interface to the user which can have answers with single or multiple choices (See Figure 51).

The assessments are then listed in the "Self-assessments" sub-section. Each self-assessment can be visualised in detail by clicking the preview button. Every time the user wishes or is asked to perform a self-assessment for a next call they can do it by clicking the "New assessment" button.

5.6.3.4. Health Monitoring

This section allows the user to analyse the values and trends of self-reported biometric data, report physical activity, monitor their level of sedentary or active lifestyle among other functionalities, such as health diaries (e.g., mood or symptom diary) or cognitive exercises. All these features were considered the most desirable after the collection of requirements. The screens developed for prototype testing, correspond to the monitoring dashboard and to the "Measurements" section (see Figure 52) that can connect to a smartwatch device to measure the heartbeat of the participants. This section includes the measurements of weight, pulse, blood pressure, BMI, blood glucose and falls. Each measurement corresponds to a module that switches bewteen a chart view or list view. New measures can be inserted in each module.

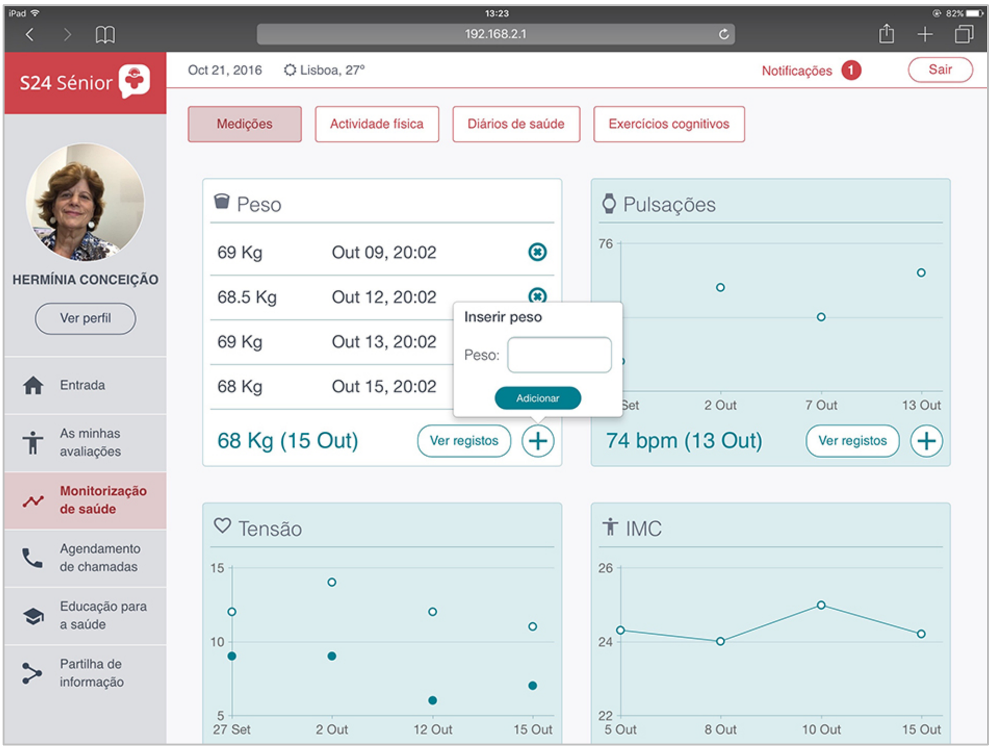


Figure 52: Measurements section in Health monitoring.

5.6.3.5. Call scheduling

The "Call scheduling" interface (see Figure 53) lists the past and future phone calls. In future calls, it is possible to see who will be the responsible nurse, what type of assessment will be made (e.g., nutrition), and the date of the contact. It is also possible to make a suggestion to change the date and time of the next contact according to the user availability. Past calls, in addition to this information, also show whether or not they have been answered by the user and what score the user assigned to evaluate the quality of care (if recommendations and the phone call was useful to them).

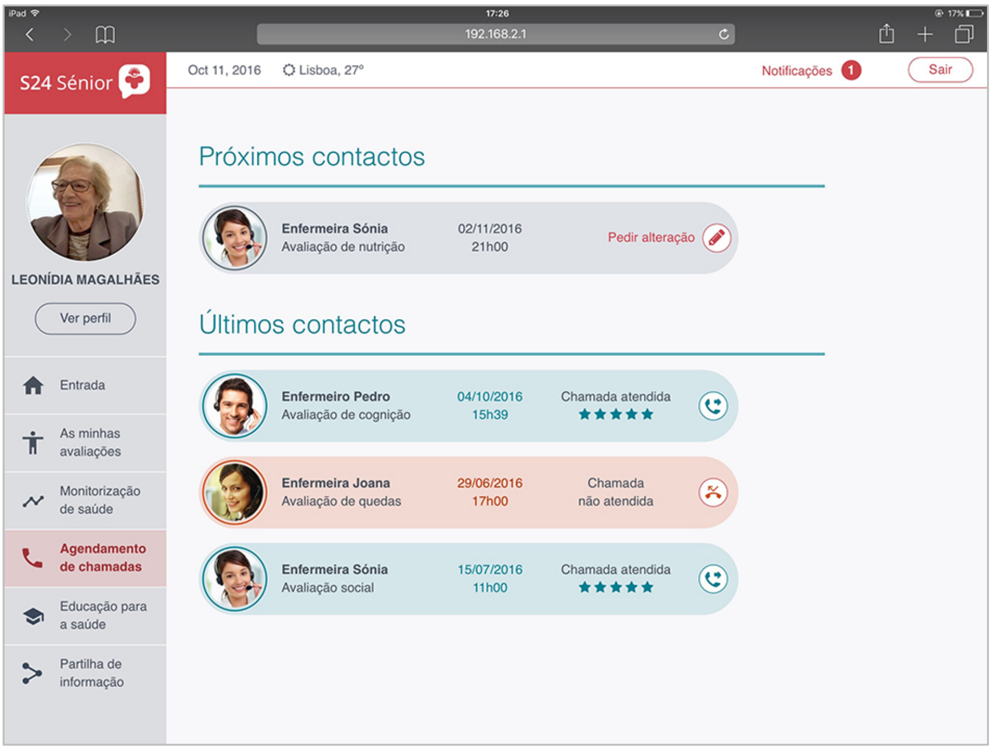


Figure 53: Call scheduling.

5.6.3.6. Health Education

Despite considering several types of health education (see Figure 38 in Section 5.5.5.12.), the prototype only includes an advisement section for testing (see Figure 54). In this task participants were asked to access the educational material area, which presents an index with training materials with the following topics: "nutrition", "physical activity", "fall prevention", "autonomy", "locomotion", "smoking", "alcoholism", "health complaints" and "suggestions for leisure time". Each of these topics provides advices on best practices with material provided by the clinical concept team of the program. Suggestions for useful readings and multimedia material, e.g., videos, were also represented in the interface but not clickable.

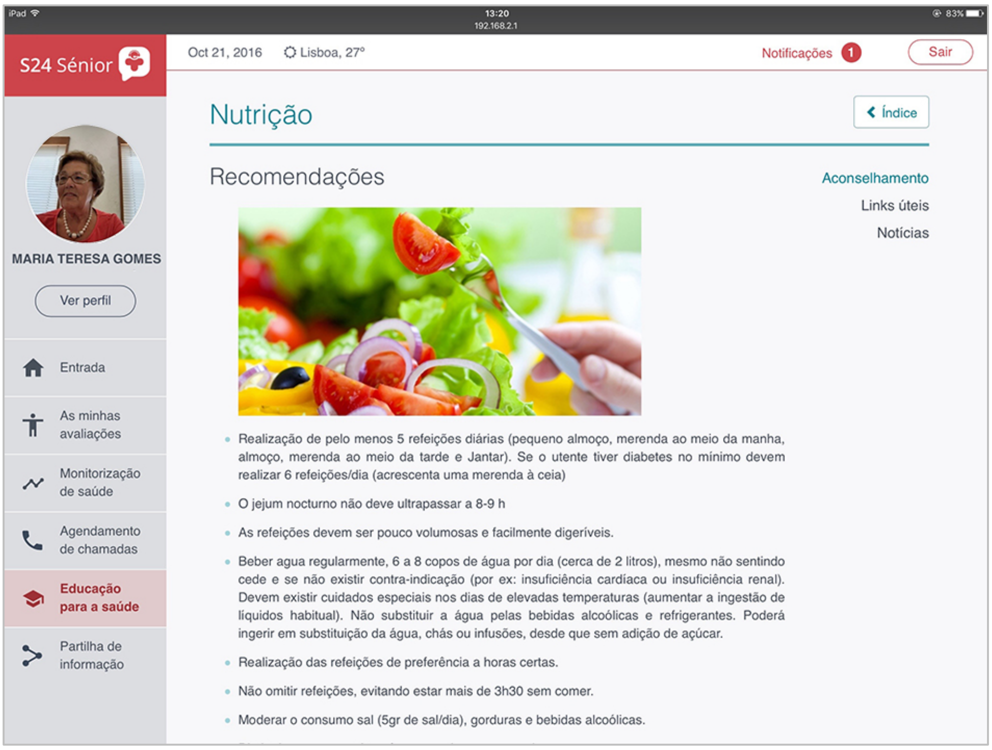


Figure 54: Health Education.

5.6.3.7. Information Sharing

The “Information sharing” section (see Figure 55) allows the user to manage the sharing of their health data with third parties, like their family members, healthcare providers or with other healthcare platforms from the NHS. In the component of sharing with the healthcare providers the user has the option of using a switch button, to declare whether or not he authorises the sharing of his recorded data in the Integrated PHR, with the Portuguese National Patient Portal of the Portuguese Data Sharing Platform (PDS). The PDS also includes the option of sharing the NHS unique summary care record with the European eHealth network. In addition, the user can consult the history of any external accesses of his data in the platform (in this case by the nurses or other clinical staff from the PDS). Finally, the user can also send or print a summary of his clinical history within the program in a readable format to be shown to a healthcare provider on a next visit. This section allows “H24 Senior app” proposal for the Portuguese Senior Telehealth Program to be integrated with the proposal for the Portuguese National Patient Portal, that was described in Part I of this thesis.

Figure 55: Information Sharing.

This last section demonstrates how Integrated PHRs can work together into cross-channel platforms that may share a reliable and sustainable structure that allows patient data to be easily shared with their providers in any environment (such as combining telehealth with primary care, and emergency assistance), which in this case, takes part of the NHS ecosystem.

Figure 56: Smartwatch app three-step user interface.

5.6.3.8. Smartwatch app

Finally, the smartwatch app consisted on a three-step user interface (see Figure 56) to measure the heartbeat of the user, as representative of the wide sensor technology and wearable devices that are available nowadays, which can be a source for collecting important physiological data, useful for the telehealth service to provide acute care rapidly to the seniors, for example, in emergency events. After initiating the app in step one, the heartbeat (per minute) of the user is displayed in the step two in the UI with a submit button, ending up in step three by giving feedback that the measurement was successfully transmitted to the Integrated PHR.

The application was developed to test the desirability of adopting these type of devices by the seniors, as a way of decreasing the burden of using self-monitoring tools by this target group, turning the measurement process of health data more natural, in the scope of the internet of things.

5.7. Prototype Development

The prototype was implemented as a Web app with a client-server structure, complemented with an Android application developed for the LG G Watch R smartwatch (see Figure 57). The Web pages were developed for tablet view layout, with dimensions to fit the 12,9" iPad Pro. According to previous studies, tablet devices are known for being well adopted by senior people, as they find touch screens easier to understand and preferable to other input devices, tending to show a more positive disposition to use them [118]. Therefore, we choose this device for this reason and also for its large size, as this user group can also benefit from large interaction targets [27]. Furthermore, an algorithm based on MAB tool was developed, to provide GHA self-questionnaires in the Integrated PHR which generate Individual Care Plan (ICP) to the users, represented by a chart that gives an integrated view over their wellbeing.

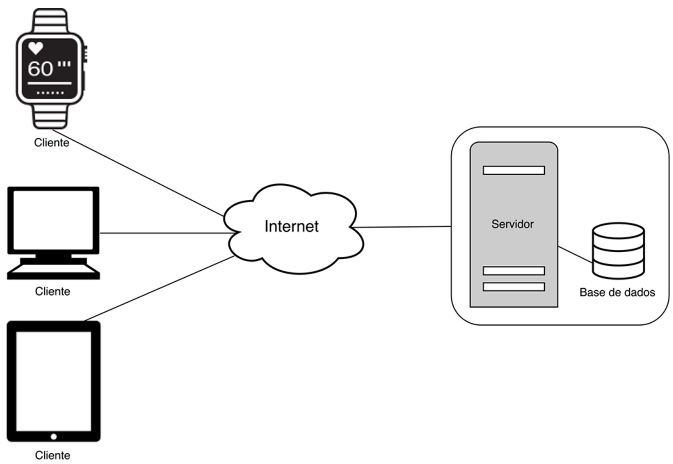


Figure 57: Client-server structure model of H24 Senior app.

The adaptation of the MAB structure (grouped into the three major health macro dimensions of Autonomy, Health and Social), as well as the way questions are formulated to be used by the seniors in a self-assessment perspective, was done in collaborative work with the original author of the tool. This participatory design session can be found in Section 5.5.2.2. More detailed information about the system development architecture, used technologies and implementation of the data base model can be found in the master thesis [22]of the student who was responsible for developing the prototype in this research work. Images of the prototype were showed in the previous section of the user interface design.

5.8. Usability Testing

The user experience of the design model proposal was assessed by conducting usability testing with a sample of current and potential users from the program. Among the hypothesis, the usability testing aimed to find out:

> If seniors could feel more engaged with the program through the online channel, by increasing their awareness about its benefits.

> If the online channel could be a way for seniors to reflect about their wellbeing and integrated health, by enabling them the access to their results and individual care plans.

> If the online channel could be a more comfortable, reserved way for seniors to answer the assessment questions rather than the phone.

> If it is gratifying for the seniors to see immediate feedback on their integrated health status after performing a self-assessment.

> If seniors feel more encouraged to participate in the management and monitoring of their health if content design reinforces their most positive side of their health.

Tests were planned to be formative rather than summative, to help forming the design and usability of the prototype. As such, we chose to focus the method on desirability of adoption (qualitative research) rather than task completion success or usability errors detection (quantitative research). The goal was to understand if the users were willing to adopt and be engaged with the application, whether they found the features meaningful and whether they would make use of them. Nevertheless, quantitative data was also recorded. Tests were lab-based with moderated sessions

22 https://run.unl.pt/handle/10362/19961

run individually with each participant. In the end of each test, a post-questionnaire was provided, applying the User Experience Questionnaire (UEQ). This tool supports the immediate user response to express feelings, impressions and attitudes when interacting with a product [33]. The questionnaire was complemented with seven final questions, to acquire the user satisfaction and how the application could enhance user awareness over the benefits of the program.

5.8.1. Evaluation Methodology

The usability tests were conducted at the Department of Informatics of the Faculty of Sciences and Technology of Universidade Nova de Lisboa and followed a scripted lab-based use approach (see Appendix G). A pilot test was run previously with a colleague from the lab to prepare the sessions. Before each test, a phone contact was made to assess the health status of each participant, applying the global health assessment (GHA), as a simulation of a regular phone call from the nurses of the service. This way, when opening the application during the test, users could have access to their results with an individual care plan (ICP) provided accordingly. This allowed the tests to be more engaging to the users by enabling them real data to interact with. Sessions began with a brief introduction about the platform, after which a consent form for permission to record data and images during the test was given to each participant (see Appendix H). Participants were also asked initially to think aloud during their session and motivated to share their thoughts throughout the test with the researchers. Task series (a total of 18) were read aloud and run with two researchers, one responsible for moderating the sessions and another who played as a note-taker and observer. After the tasks completion, participants were asked to fill the post-questionnaire (see Appendix I).

The usability study was voice recorded and applied both qualitative and quantitative research. In qualitative research, participants were asked exploratory open-ended questions during the tasks which focused on their perception about the visualisation of information and their emotions towards the product interaction. After performing each task and depending on the research goals, specific questions could be asked about conceptual aspects of the application through subjective measures in order to understand the product desirability. Responses followed a 5-point Likert scale or could be only Yes or No. User opinions and recommendations were also collected. In quantitative research, each task was also evaluated by the task completion success rate and by identifying the most critical errors. During the test, the moderator provided help to complete the task, only when necessary. The tests used the following equipment:

> iPad Pro, in which the application was used;

> Voice recorder;

> Smartwatch LG G Watch R.

5.8.2. Participants

The recruitment of the participants for the usability test falls into two user groups. (Group A): 7 seniors who are part of the program, including 5 who participated in the previous user research stage. (Group B): 3 seniors who were not part of the program and who were also new to the study, recommended by one participant from the other group. This sample represents a total of 10 participants.

Group A represents current users from the program while group B represents potential users. Also, group B contributed to avoid any social desirability effect that could derive from group A, who were familiar with the program.

Our goal was to understand if the design of the system worked for these two groups, testing (1) if the design reflected the interaction with the program, enriching the awareness of current users about their wellbeing and follow-up care process. (2) If first time users in the program (group B) could perceive the way the service works, evaluating their interest in joining through the web.

Age	Gender	Education level	Marital status
74	Male	Graduate Degree	Married
90	Female	Graduate Degree	Single
80	Male	Graduate Degree	Married
70	Male	Graduate Degree	Married
80	Female	Secondary School	Widow
75	Female	Secondary School	Married
88	Female	Basic School	Divorced
65	Female	Basic School	Divorced
76	Female	Secondary School	Widow
71	Female	Graduate Degree	Married

Table 4: Participants demographics

We recruited a sample of well-educated seniors (see Table 4), as representative users of the system, who are about 25% from the total amount of the people enrolled in the program, according to an estimation provided by the program. Although this sample corresponds to a minority group of the program participants, we decided to start our research with people that have prior Internet knowledge, as preferable inclusion criteria. Again, for the same reason we chose the sample of seniors in the interviews, future older adults are expected to be more proficient in computer use [69]. In our sample, five participants are graduated, three have secondary school and the other two have basic school. Their occupations before retirement included army officer, librarian, teacher or tailor.

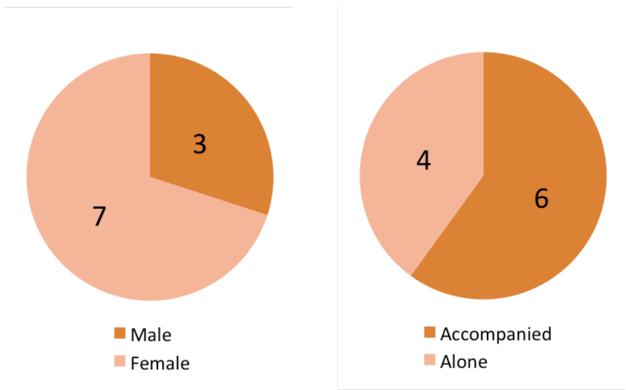


Figure 58: Genre (left) and if live alone or accompanied (right).

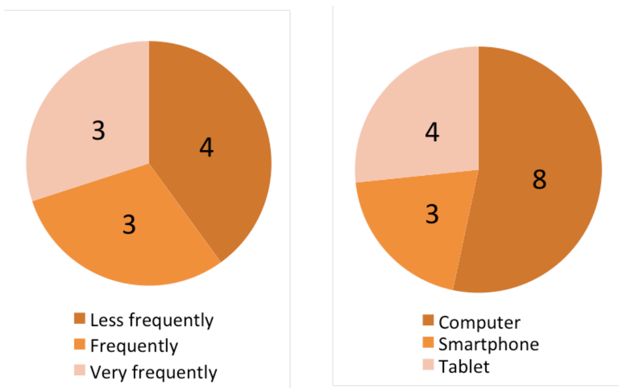


Figure 59: Frequency of Internet use and used devices.

The age range of participants was between 65 and 90 years old, resulting in an average age of 76.9 year old. Six of the participants live with a spouse, while four reported living alone (see Figure 58). In terms of frequency of Internet use, four said to use infrequently, three frequently and three others, very often (see Figure 59). Four of them used tablet and from these, three also used smartphone. Eight participants could count on family support, while two said they did not have such support. Only one participant has ever used the Patient Portal eHealth services.

5.8.3. Findings

In this section we describe the findings of the usability testing that was performed to assess the user experience of "H24 Senior app", grouped into eight use case scenarios listed accordingly. The scenarios were divided into several tasks that diverged from tasks based on real life: e.g., "Imagine that the nurse had asked you by the end of a last call, for checking until the next follow-up, if you were able to put the advised recommendations into practice. Where would you perform this task?"; direct tasks: e.g., "In order to personalise your user profile please answer the questions on the screen"; or exploratory tasks, e.g., "We would like to ask you to access your last assessment and interpret the chart and describe aloud what you are visualising". All layout descriptions were described in the User Interface Design Section 5.6.3. of the previous chapter.

5.8.3.1. Use Case 1 - Create user profile

The first use case of the test consists of only one direct task, in which participants were asked to answer a set of questions to customise their user profile (see layout in Section 5.6.3.1) with information useful to the program and registration workflow. All participants responded correctly to the presented questions, navigating step by step through a wizard titled "Tell us about yourself" (see Figure 60). The navigation was natural for the participants, although some needed an initial adaptation to the interface, in which two usability errors were detected (errors are described in Section 5.8.3.9). S5 of 90 years old, the oldest participant, commented that the questions were clear and the response to the registration form was straightforward, stating "It's funny because it's totally different from what I use in my tablet and the way the questions are asked is easy to understand and easy to handle".

The question that generated the greatest controversy among participants in the user profile from the registration form, especially among those who live alone, was the definition of the family context. In answer to the first question, "Do you live alone or accompanied?" (answer options: alone/with spouse/child), S7 asked for the possibility of including her dog, her life companion, in the set of answers in order to respond that she does not live alone.

Concerning the question "Do you have any family support?" (answer options: yes/no), S3 said, "I have some family support but not all that I needed. Usually, I feel alone because they call me only once or twice a week, but I prefer to answer Yes rather to a No". In the end, she added that there should be another option of response, such as "some support" or a numerical scale. Participant S6 explained: "I cannot count on family support because I do not have my children here, they live abroad, but I am in doubt. On one hand I cannot say no, because if I am very sick they can possibly come to see me, but usually they cannot leave their work. So in my situation, I go to friends if necessary, so I'll say no".

Figure 60: participant answering to her family context during the user profile registration.

5.8.3.2. Use Case 2 - Explore the dashboard

When entering the application, we asked the participants to describe aloud the visualisation of the dashboard (see layout in Section 5.6.3.2) which is divided between the "Care Plan" view and "Monitoring" view, in order to evaluate the concept design. "Care Plan" view presented real data of the user in a summary of the "Last global health assessment", populated with the results of an evaluation performed over the phone with the participants, the day before the test. The goal was to simulate a contact made by a nurse in the program engaging the user in a more realistic user experience. "Monitoring" view presented simulated content about the user self-monitoring data.

Explore care plan view

What raised most impact in this dashboard view was the representation of the "Last global health assessment", with the results generated from the answers obtained in the assessment conducted by phone, previously to the test. However, this simulation was not intuitively understood by the participants in a first approach. Most of them showed difficulties associating the results with the responses they had given on the phone, yet, after a brief explanation, they showed curiosity on having their wellbeing represented in a visual way, focusing mainly on its interpretation during this task (this interpretation is further explained together in the next use case that shows in detail the access to the last assessment in the application).

During the interpretation of this dashboard view, most of them tended to diverge from the task and describe instead, how they felt and what were their current problems. This dispersion occurred while analysing the results of the Autonomy, Health and Social domains in the summary of the last assessment care plan. In several cases they also showed in a positive way, a sense of pride, on comparing their health with their friends or people of the same age in order to report good health. Some of the participants made a more linear reading about the summary. For example, S6 reported: "I have health complaints that take away my autonomy and will of going out and do things. On the emotional level I am aware there are some problems because I live alone…however my view about my state of health is quite good, so I agree with what is here".

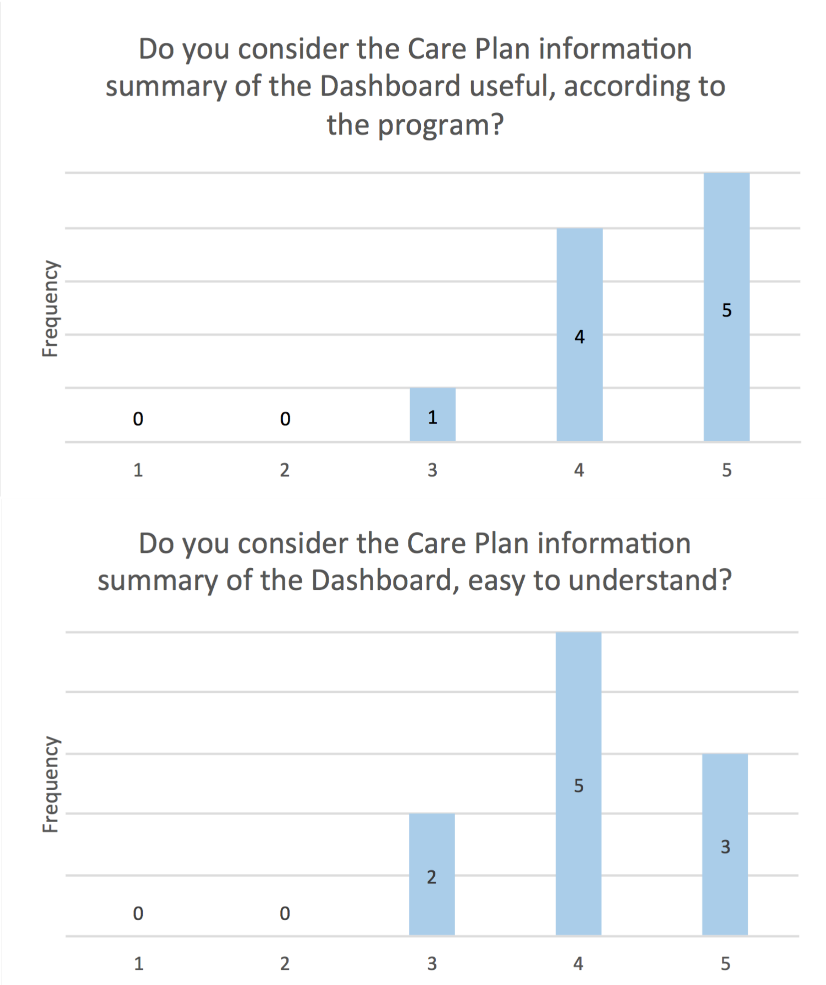


Figure 61: Histograms of responses to script questions of the task 'Interpret care plan view'.

Despite dealing with some "surprise factor" in the first impact of this task, according to S8 "this is a bit new for me", by the end, all the participants understood and valued the quick view over the summary of their care plan and interaction with service. S2 thought she was being tested by the nurses as they she was asked the same questions, everytime she received a new cal, explaining:

> *"This part (web) shows what's important, as it displays the good things and the limitations that people have. If we could see this, when they're calling, it would be very good."*

S3 also commented "It is useful to be aware that we have a next follow-up call on a certain day and to know the state of our last evaluation." At the end, participants answered to quantitative questions that can be seen in the histograms of responses in Figure 61.

Explore monitoring view

In general, the dashboard was well accepted by most participants. The proposed gamification functionalities that motivated the users to develop their daily physical capacity by encouraging them to "compete" in a positive way, were of the participants interest. In this screen, the greatest difficulty was the abstraction from reality to interpret the simulated data as a proof of concept.

To the question "Would it be interesting to establish daily goals with the nurse, negotiated during the periodical calls and monitor them through this application?", only one participant gave a negative answer. S3, S8 and S9 considered that setting daily goals could stimulate interest in doing physical exercise, motivating people and making them feel more fulfilled. According to S3, when people are inactive they become unmotivated and the program can encourage them balancing that trend. S4 highlighted that scoring goals is a very positive attitude because people make commitments:

> *"It is a way for people to make commitments and motivate them to overcome their difficulties like pain itself, which can sometimes take part of certain physical exercises recommended by the nurses, which in the long run, are beneficial."*

Other participants have reported that they may lack the time or willingness to consult and carry out the recommended activity on a daily basis, as they do not want to have commitments. S1 suggests that daily goal monitoring could be performed weekly instead of daily. S6, who had a low score at the emotional state, said she was afraid of failing the goal, which could be frustrating on certain days.

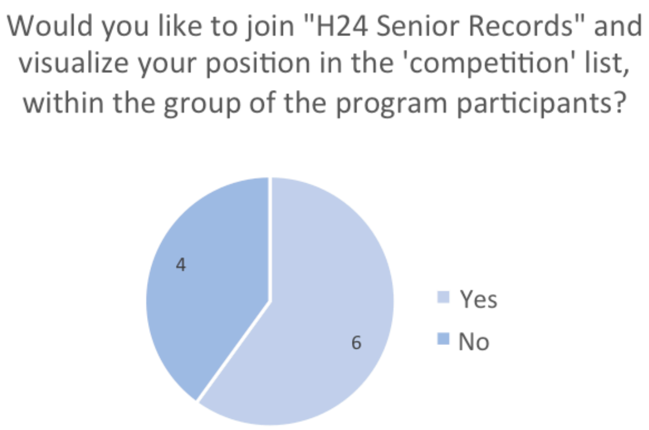
To the question "Would you like to join H24 Senior Records and visualise your position in the list, within the group of other participants enrolled in the program?", 6 participants answered "Yes" and 4 answered "No" (see Figure 62). Participants who answered "No" justified by not being supporters of competitions or not wanting to accept commitments they might not be able to meet. S7 explained, "I'm very independent, I have my own rhythm and it would be an obligation for me, to get into that system."

The most appreciated reason for participants who answered "Yes" was that this feature could be an incentive for people to practice physical activity, as there is a tendency among seniors to compare themselves. S1 commented with satisfaction, "I am unintentionally competitive. I do not like being the last and trying not to be the last, most of the time I end up being the first in everything." S2 explained "People of our age usually take pleasure in comparing themselves with the less active ones" but shown some concern about the lack of personal relationships, continuing:

> *"These things take away the social relationship, the problem with machines is that they may lead to less human interaction..."*

To the question "Do you think that this feature could be an encouragement, not only for seniors to practice their goals, but also to help avoiding social isolation in some people?", the majority showed agreement (see Figure 62). Some other participants suggested increasing communication and the user interaction through this feature. S9 commented "People who start to have incentives could start talking to each other." S5 suggested "This could also promote communication among people in the program, a stimulus that increases while the person starts to feel better by getting to know other people." For S4, this feature seemed almost mandatory, "Communication can help breaking isolation. Without that, the individual who is in first place on the competition list will be very happy while the others that may not accomplish their goals, if they are competitive they can become discouraged."

To the question "Would it be useful for you to know weekly, by measuring with a smartwatch, whether you have had an active or sedentary life?", 8 participants answered "Yes" and 2 answered "No". Among the majority who answered "Yes", S7 argued that he would like to know if his life is within normal parameters. Those who did not think it was useful, argued that they know in advance whether they are active or sedentary, not having the need to monitor through a watch. S3 stated "As I am aware of my status, I usually know how I am, I guide myself by what I feel."



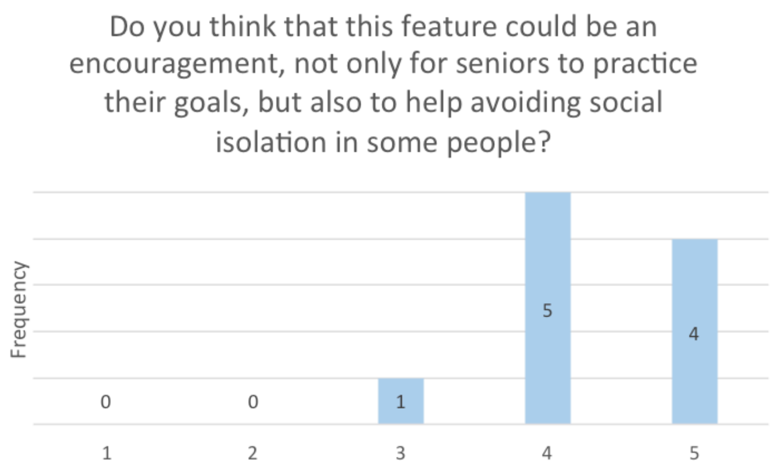


Figure 62: Histograms of responses to two of the script questions of the task 'Interpret Monitoring view'.

Respond to humor notification

To the question "Do you consider it relevant to share sporadically, how do you feel, with the nurses who follow you in the program?" All participants answered yes. Most of the participants said it would be nice to be asked how they feel, because it makes them feel less alone and concerned about. They all answered in a task, during the tests, how they were feeling in that moment (see Figure 63).

S1 suggested to "share every day how I feel with the nurses but without having to always access the application, for example by using that smartwatch." As a complement to the mood feature, S6 suggested that there could be more communication in the program, besides the voice:

" It would be valuable to also see who is on the other side. There is always an expression in the face, a smile, which I think is important. Now we have an inquiry, a formal thing."

Finally, S4 mentioned that it would be helpful for nurses to be able to provide support through the application after accessing the mood report of the individual: "I would help them, by allowing them to help me."

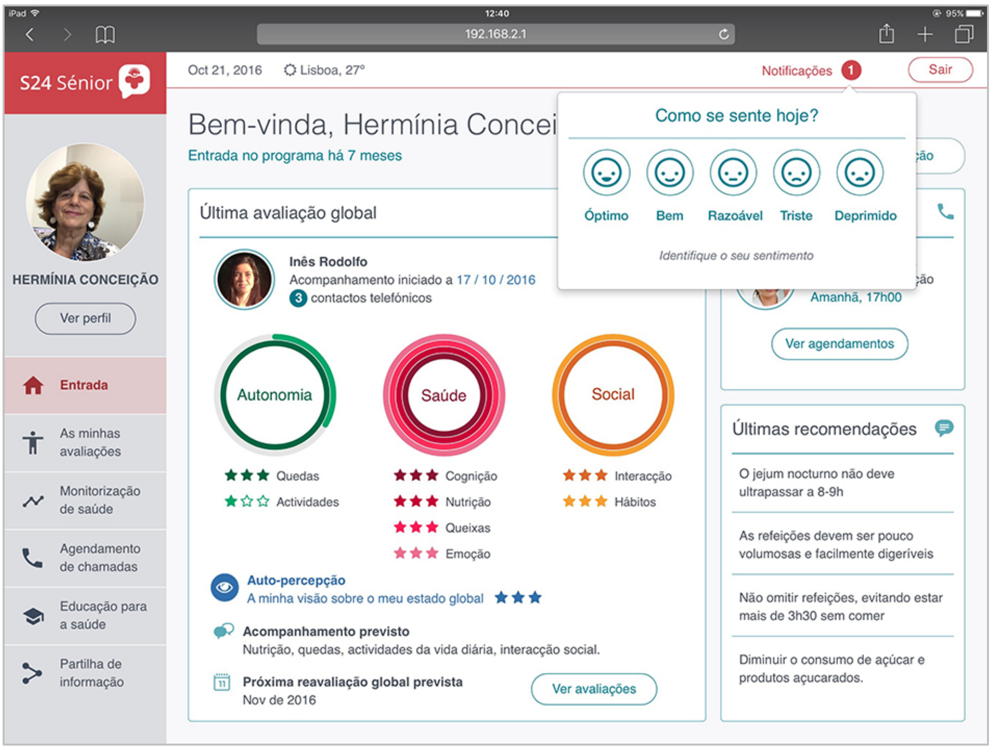


Figure 63: User responding to a mood notification.

5.8.3.3. Use Case 3 - Access to the last global health assessment

The data from the GHA results can be visualised through two different chart proposals: chart A and chart B. The goal in this task was to explore integrated data visualisation techniques to capture the integrated health of the senior so they could reflect and become aware of their wellbeing.

Interpret data visualization: A/B testing of the chart

The two chart proposals were inspired on two previous studies from literature review but designed with divergent approaches in both cases, also based on current trends in the HCI field. The displayed data in the charts consists of the assigned scores (from 0 to 3) for each of the evaluated health microdimension. Chart A is composed (see Figure 64, left) by rings grouped into the three donuts that display the three health macrodimensions with the attributed colours, respectively: Autonomy (green), Health (magenta) and Social (orange). Bellow the donuts, the chart has a legend with three stars that maps the score for each ring (from 0 to 3), through gradient colours derived from each donut. Chart A was inspired on a partitioned donut visual display from the study "Integrated data visualisation: an approach to capture older adult's wellness" [97] and on visual display trends for healthcare activity tracking e.g., apple watch Activity app[23].

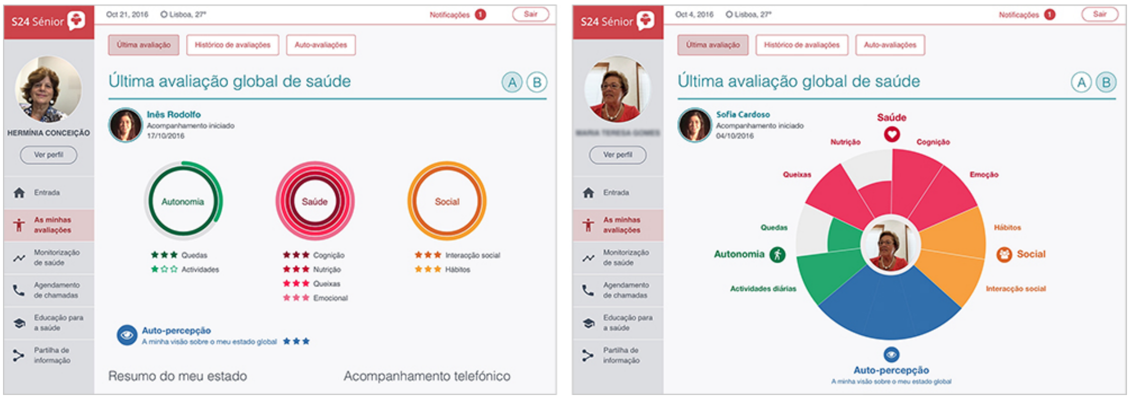


Figure 64: Chart A (left) and chart B (right).

Chart B (see Figure 64, right) is composed by a radial bar chart that groups all the three categories together in the same "wheel", divided into segments for the several microdimentions, also distinguished by the three main colours, but without any gradients. This proposal was inspired in the study "YourWellness: Designing an Application to Support Positive Emotional Wellbeing in Older Adults" [46]. We decided to present a parameter from the assessment tool that evaluates the self-perception (measured by the assessment tool), highlighted separately from the three macrodimensions (represented in blue), to test if the perception of how seniors see themselves, compared to how others evaluate them, was relevant to them. While in chart A, this parameter is presented separately and below the chart, in B it is presented integrated within the chart, with major visual impact.

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23 (https://support.apple.com/en-us/HT204517)

In A/B testing, despite that users were already familiar with Chart A from the previous task, they chose chart B as the most understandable and easy to read (except for one participant) and attractive one (all agreed).

Although participants, in general, understood the display of chart A as S1 interprets: "Here my health is not completely well, because I would like the rings to be united and they are not"; there were several questions raised in its interpretation by some participants who reported the main problems:

- Interpretation of the meaning of the stars' caption and their association with the chart rings: S8 interpreted the three star score in the "emotion" field as being a very emotional person rather than being well on an emotional level.
- Interpretation of chromatic gradients in stars' caption: despite making a good relation between the caption and the rings, S3 interpreted the magenta colour gradients as worse and the green colour gradients as better. She explains, "maybe I would better understand if the colours were all the same". Also, S6 and S9 thought that their health was not good in microdimensions where the rings were completely filled (meaning they were well), because the associated color was less vivid.
- Interpretation of the descriptions: some microdimension descriptions of the chart are not clear to some of the participants, as is the case of "Habits". Although it makes sense for healthcare providers positioning "Habits" under "Social" macrodimension, for the users, it was often mistakenly interpreted. Instead of associating with alcohol and tobacco consumption, for instance, they associated it with meeting their friends, or going out for walks.

The main reason for chart B preference was because of its "wheel" shape that groups all the information together, which allows an easier perception of the whole, better differentiating the individual's evaluated dimensions. S1 said:

"The most understandable is B, it gives me the full picture with the slices of the respective areas. It is a global and fast visualisation."

The participant also added in his interpretation "If there are complaints, emotionally I can not be well either, it makes sense to be in opposite sides as we see in the chart." S3 and S9 also explained that while in chart A the various circles make the user jump from side to side and to follow up the fill of the rings, in B it is immediately seen whether the slices are larger or smaller, encompassing everything in the same area, requiring less cognitive load from the user. S8 and S3 added that they also better interpret the shape of B chart because it reminds them of a bar chart which they are more used to. Nevertheless, one participant raised an issue regarding the design scale of chart B, saying that it is more complicated to perceive how much larger is, one slice than another.

Concerning self-perception, the concept was well interpreted by the participants and considered to be relevant information to stand out in the GHA. Again, chart B was preferred by most though one participant had asked "why there is so much room for self-perception in B". S9 analysed self-perception in the following way:

"My view on my health includes everything: health, autonomy and social, and this is concerned to my perception of this whole, which I find interesting to be aware of."

Also, S9 showed interest in being able to click on one of the slices of chart B to know more information about a given score. Thus, the participant suggested increasing the user interaction:

"The possibility of clicking on the status could be offered, giving more information about the meaning of the results. Recommendations could also be associated with each result, including motivational messages."

Interpret summary of my condition

All participants read aloud the summary of their condition in order to better understand the results of their assessment, arousing their curiosity. Some participants made suggestions for improving the content. S2 and S6 suggested to change the evaluation of self-perception: "In the summary says that I have a very positive view of my health, but perhaps it should say only 'positive' or 'more positive' than others in my age and gender" (S6). Other participants also countered: "I get up or walk without difficulty"; "I have difficulty getting out of bed, spending a lot of money on mattresses"; or "I do not drink wine." S6 proposes "maybe I should say" regularly " because there are people who only drink occasionally".

S9 suggested that when there were no marked improvement points, a motivational message could be shown to the user so people can continue with their good health habits. Although it was not part of this task to follow the related links in the "points to improve" that led to the educational material some participants clicked on the "learn more" button on their own initiative. As an example, S8 decided to read the advice on how to prevent falls (here the presented material corresponds to real content, provided by the program).

Figure 65: Participant answering to recommendations.

Respond to the phone call recommendations

During this task, users were asked to give feedback to the nurses about a set of recommendations. To this end, they successfully interacted with a set of UI check boxes to answer if they could put them in practice (see Figure 65). All participants considered useful both for them and for the nurses, to respond to the phone call recommendations, identifying advantages in this feature. S2 considers that it turns out to be more concrete through the web than through the phone, because the person can have more time to reflect on how she feels when giving feedback on recommendations left by the nurses. S8 and S9 argued that sharing this information with the nurses could result in a better personalisation of recommendations: S9 commented "It is very useful because the nurse can see what is happening to the person in a certain moment and over time".

Comment and possibly share the assessment results

During this task, users were asked to comment the results of their GHA (see Figure 66). All participants appreciated the possibility for commenting on their assessment or ask for any clarification to the nurses about their results. Since it was an open-ended task, some participants did submit comments directly related witht their wellbeing results, but the majority choose to comment about the test session experience instead, possibility considering that a lab-test environment was not the most appropriate moment to reflect about their condition. S9 interpreted the feature as a way of sharing with the program staff how they feel after reading the results. Other participants, to whom initially this feature was not clear, suggested changing the title from "Comments" to "Doubts" (S2) or "Need to contact in special situations" (S5). S4 also mentioned that the comments chat area is important for people to feel they are part of the process and S5 to better understand how the program works: "I think it is relevant because people may have different ideas about how the program works and so they can ask questions". Finally, S7 reported that this functionality could be useful in case of having questions or difficulties in taking medication.

Figure 66: Participants submitting a comment.

To the question "Would you like to have the possibility to share the results for a future medical appointment?", all participants answered, "Yes", except for one. Several participants recognised the usefulness of sharing information about their follow-up records in the program, particularly with the family doctor. S2 and S8 showed immediate interest in the possibility of sharing the data. According to S2,

"I would love to use it! At the moment I currently take a printed Word file with me about my clinical history, to share with my doctor."

Some participants showed concern about the lack of time that physicians often deal with. The participant who answered "No" to the question explained "they (physicians) have such a short time to spend with us, once I took some notes in a paper to discuss with a doctor about my symptoms and he told me that he had no more time to spend." Nevertheless, the general opinion was that such a summary record could complement the work of the physicians. S10 commented: "I would like to send this information to my doctor from the health care center, I know he would be very receptive! The worst thing is that later, possibly he would ask me to do more tests."

Evaluate the quality of care

To the question "Do you consider evaluating the quality of care during the calls can be useful, both for you and for the nurses?" All participants answered "Yes". S4 justified the answer saying that it is mostly useful for the service supervisor to realise if everything is being done correctly according to the program procedures. S6 suggested a new field of free text to explain a possible unfavourable feedback of care.

5.8.3.4. Use Case 4 - Access to the assessments history

The "Assessments history" is divided into two views: the timeline view and a chart evolution view, and its main goal was to give the users a temporal perception of their health evolution in the program, over time, with simulated data for the usability test. For layout description, access section 5.6.3.3. in User Interface Design chapter.

Interpret timeline view

All participants were able to interpret the timeline, regarding their enrolment in the program, over time. To the question "How useful do you consider visualising the several interactions with the program in this timeline format?" from 1 to 5, eight participants answered 5 and two participants answered 4. Apart from S6, who said she had no interest in observing the evolution of events over time, only showing interest in being aware of her current state, all other participants showed interest. To the question, "Are nurses' photos a plus? Meaning in the long run, do you think they would help to generate empathy during the phone calls follow-up?" All participants answered, "Yes." S10 commented:

> *"I like to see people, not being just words would give us a more loving and close contact."*

Likewise S9 also commented "It is different to talk to a person knowing her face, there is more empathy, in fact." S1 went further and said he had already suggested to the nurses of the program to make the contacts by videoconference. S3, despite wanting to see the faces of the nurses she communicates with, expressed concern about her privacy, reporting that she preferred not to show her own photo to the nurses.

Interpret chart evolution view

In the second view, users where asked to randomly choose and click in a date from the chart to interpret the information of their progression within the evaluated health dimensions from the program, Health, Autonomy and Social. When clicking on a specific element in the chart, a tooltip is shown comparing the results of this evaluation with those of the previous one, indicating to the user where they have improved, maintained or worsened their state.

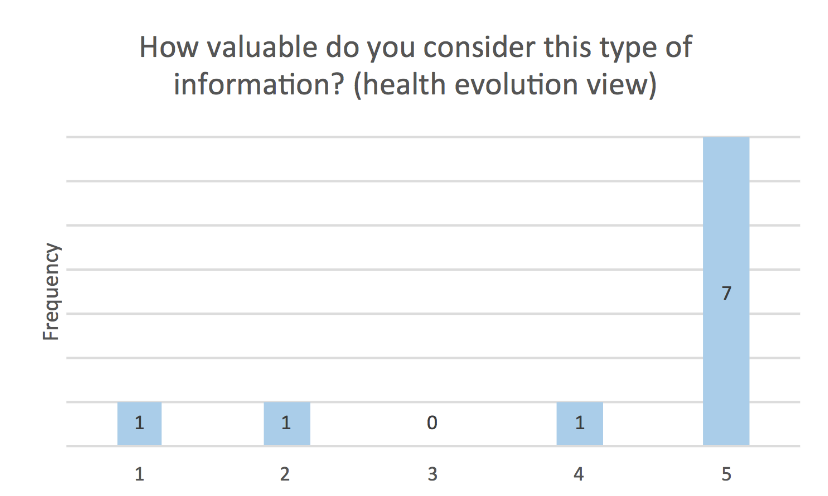


Figure 67: Histogram of response to script questions of the task 'Interpret chart evolution view'.

Answering the question "How valuable do you consider this kind of information?" (see Figure 67), S5 and S7 reported they did not need or wanted to see how their health is evolving, only caring about the present moment. S3 also argued she currently did not want to see trends in her health condition for feeling emotionally vulnerable.

On the other hand, S1 found this feature of great utility, having been pleasantly surprised when the chart was presented, being able to know about his improvement in a given date. S2 commented "it is good to be able to see the this kind of information detail, when we get worse is a warning, when we improve is good for us to know about it."

S9 found it rewarding, explaining:

"People naturally forget what happened the week before. Therefore, accessing this information enables me, for example, to talk to a nurse if my condition has worsened, while if improves, gives me the awareness that I have been correctly following the recommendations."

When evaluating the interaction with the chart evolution view that represents the several health macro and micro-dimensions results over time, one usability error was detected, since 5 participants tried to click on the dates represented in the horizontal axis of the chart instead of the points, when asked to see more detailed information on a certain date. S4, before realizing that the chart was clickable, stated that there should also be some absolute reference on the vertical axis for better understanding the data.

5.8.3.5. Use Case 5 - Perform a self-assessment and access to educational material

To perform a self-assessment, a questionnaire that applies the adapted GHA, presented 22 questions in an overlay interface to the user (see Figure 68). In the end of this task, after the results were displayed, we asked the participants to access one of their "points to improve", presented in the summary of their condition. For layout description, access section 5.6.3.3. in User Interface Design chapter.

Figure 68: Participant performing a self-assessment.

User feedback on self-assessment

All participants were able to answer the questionnaire, interacting very naturally with the UI elements for answering the questions with single or multiple choices. Participants made some remarks about some questions and the given results, expecting to have a higher score, e.g., in the "activities" field, part of the Autonomy dimension. After we explained that using a hearing aid is what caused the score of 0 in that field result she argued that it did not make sense for her: "If I do not listen even with a hearing device, I may have some trouble performing certain activities, but if I do listen with a device and I am able to perform my activities then my Activity field can not be scored 0!"[24] Other participants also questioned some other scores of the assessment. For example, S6 does not agree with her 3 star score emotional state in her results stating that it does not correspond to the reality, referring having many mood swings during the day. To the question "How rewarding is it to visualise your integrated health status, immediately after the completion of the questionnaire?" one participant answered 4 and nine answered 5 in a 5 point scale. All participants considered it to be rewarding to perform self-assessments. S1 was pleasantly surprised:

"I instantly know all my data? It's very gratifying!"

S10 justified the answer saying "This way I can know how I am without having to upset doctors, without the need to always make appointments." S2 added that, even with negative results, it is always good to know the person's condition: "I stand for open information, even if the person is ill, it is good to know." However, S5 who was in a more vulnerable state has shown some concerns: "Generally yes, but it depends on the days and condition we are in."

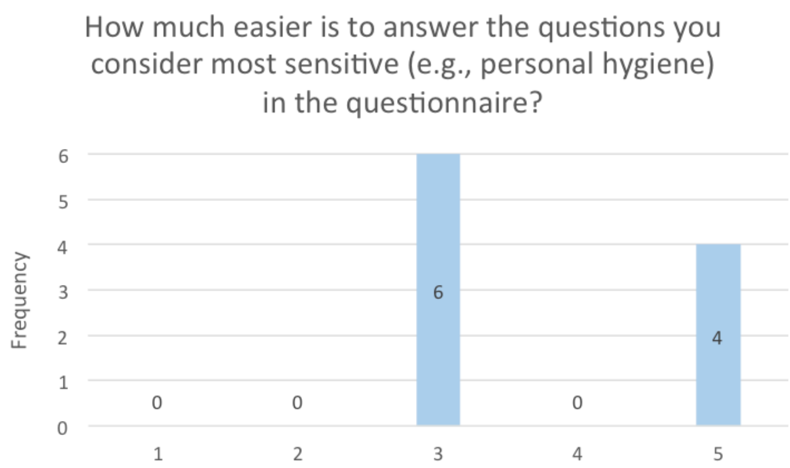


Figure 69: Histogram of responses to one of the script questions of the task 'User feedback on self-assessment'.

24 This score does not correspond to the set of the original MAB tool. It was adapted by the H24 Senior Telehealth Program.

As for the question “How much easier (compared to the phone) is it to answer the questions you consider to be most sensitive (e.g., about the personal hygiene) in the questionnaire?” (5 means more easy and 1 less easy). Responses were quite divided (see Figure 69). For six participants an online answer or answer by phone is the same for them. S10 mentioned: “It's irrelevant, I'm a talker and I easily tell what's going on with me, while there are people that prefer not to be exposed,”- As for other participants, the privacy that the self-assessment offers is an opportunity to talk more openly about certain issues. S2, who answered 5, explained:

“There are certain issues that I would prefer to answer in here, related to sexuality, which for many elderly people is a taboo.”

Access to related health educational material

As an open task, the participants were given the choice to access information about an improvement point that could be relevant to them. The access to the educational material could be done by clicking in “Learn more” button, associated with each of the improvement points identified in the “Summary of my condition” part of the self-assessment results. All participants were able to complete the task without help and considered to be in their interest to be able to access educational material on their points to improve. S6 accessed to the prevention of falls, considering the contents useful to her, for having fallen in recent times. S8 was able to access two different contents on different points, interacting naturally with the application and reading the full contents, delving into the subject. S10 justified the willingness to access the educational material as “the person becomes more aware and takes the steps that consider necessary to manage her health”.

5.8.3.6. Use Case 6 - Self-monitoring

This use case explores two tasks that represent both manual and automatic inputs of data by the participants in the Integrated PHR. Other features about self-monitoring were previously explored by concept design in Dashboard Monitoring view of the second use case of these findings. For layout description, access section 5.5.3.4 in User Interface Design chapter.

Insert weight measurement

In this task, participants were asked to submit a new record with the value of their weight. Only six participants were able to complete the task without any help, while the remaining four had difficulty recognising the insert button designed with a plus

"+" icon. Thereby, it was possible to perceive the need for having descriptions in all buttons in the design for senior people, avoiding isolated icons for UI interacting components. After opening the pop-over layer with the input field to record the weight value, all participants were able to submit their weight without any problems.

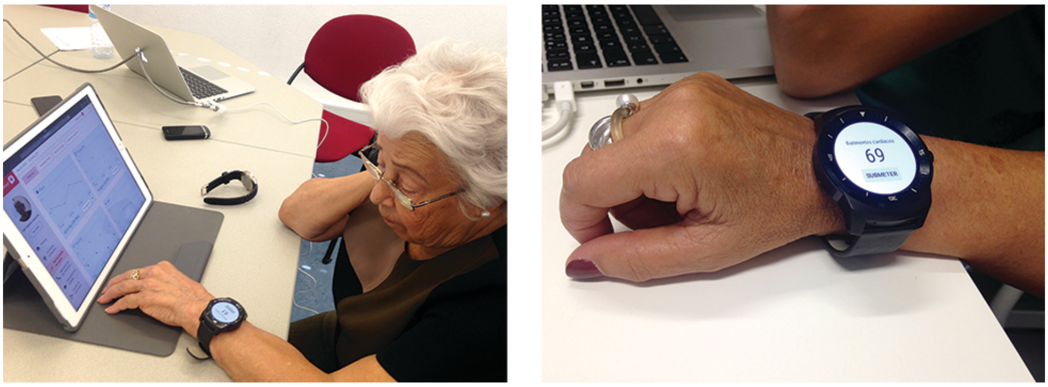


Figure 70: Participant measuring her heartbeat through a smartwatch.

Monitor heartbeat

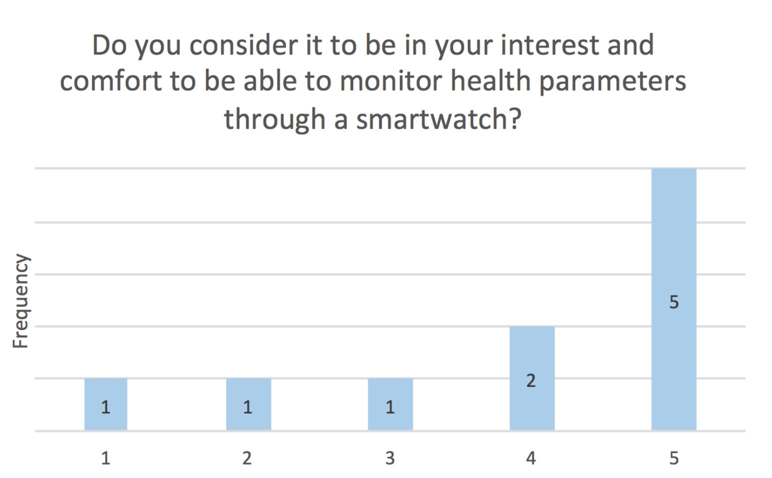
In order to measure the heart beat of the user in this task, a LG G Watch R smartwatch was placed in the participant's wrist (see Figure 70), which displayed to the user another application developed for transferring the measured heart beat to the platform.

To the question "Do you consider it to be in your interest and comfort to be able to monitor health parameters through a smartwatch?" on a 5-point scale, despite the majority answered 5, there was some dispersion of responses which can be seen in Figure 71.

S10 said it was valuable to be able to visualise his heart rate on a daily basis. However, there were also other participants who stated that this type of technology was not of their interest. S3 said she did not see the need to use a new device and S7 mentioned the possibility of only using it when he felt less well, to control the values.

In response to the question "Do you think monitoring health data could increase your anxiety, having a negative impact in your well-being?", from 1 to 5 (where 5 represents greater anxiety), four participants answered 1, two responded 2 and four responded 3, showing lower tendency for increased anxiety (see Figure 71).

For some participants, monitoring health data was considered only to bring benefits and no anxiety. On the other hand, some participants, such as S3, had an opposite opinion, arguing that having abnormal values could increase anxiety.



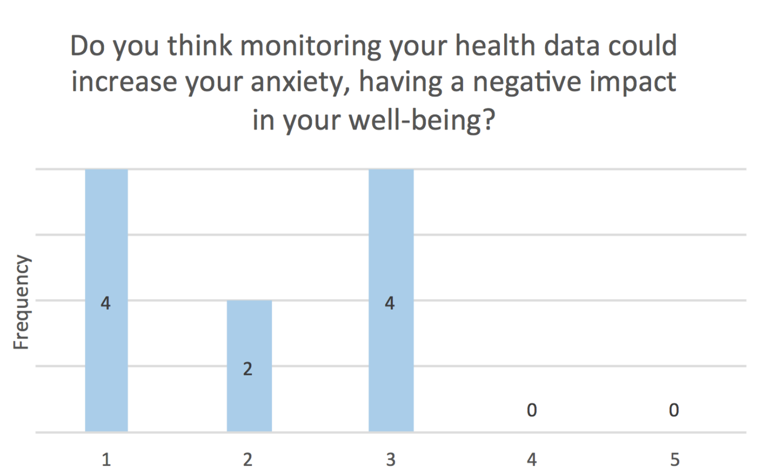


Figure 71: Histograms of responses to script question of the task 'Monitor heartbeat'.

5.8.3.7. Use Case 7 - Access call scheduling

In this task, users have been asked to access the call scheduling section (see layout in Section 5.6.3.5) so that they could consult information about past and future contacts.

Interpret call scheduling

The participants were able to access and understand the screen without help. All participants demonstrated interest as users of the program, especially highlighting the possibility of requesting the change of date or time of a scheduled call. S1 commented "It would be very useful to know when the next calls will be or ask for some change, because this way we would avoided missed calls."

Two usability errors were identified in the interaction of certain users with this screen. S4 thought that the "ask for change" button was to change the nurse responsible for the contact and not the date or time; When S9 saw a 5-star rating in one of the past contacts instead of interpreting it as the quality of the care provided during the call, she thought that was an evaluation left by the nurse about her health condition in that call.

5.8.3.8. Use Case 8 - Sharing data with the National Patient Portal

In this task, participants had access to an explanatory text about what is the Portuguese Health Data Sharing Platform (PDS) and the National Patient Portal (addressed in the first part of this thesis), showing the advantages of its use and the possibility of sharing the contents of this app with the PDS.

This task suggests how both proposals from part I and part II of this thesis can be connected within the NHS ecosystem through the Integrated PHR model. For layout description, access section 5.6.3.7. in User Interface Design chapter.

Enable data sharing

All participants were able to access the information sharing management section without any problems. Among the participants, only half already knew the National Patient Portal and only one had already used the eHealth services. After reading the initial explanatory text, all participants showed an interest in sharing their health information with the PDS platform.

S8 showed some concerns in accepting the data sharing and wanted to read more about it. The only participant who had previously used the National Patient Portal, was unpleased with the current functioning of the platform, sharing his experience during a rencent appointment at the National Oncology Institute, while being prepared for a surgical intervention:

> *"I was asked what was the name of a medicine to which I'm allergic to. I answered that it was on my personal health record of the NHS Patient Portal. They answered they couldn't access it, making me send an e-mail with the name of the medication, later on."*

This participant expressed concern that in case of an emergency accident, the failure to access the platform can be a danger for the person and for the overall functioning of the NHS.

5.8.3.9. Task completion success rate and errors report

During the task series, the success rate and main usability errors for each task were note-reported by the usability test observer. As the main goal of this evaluation was to test the application as a proof of concept design, focusing mainly on the user desirability for adopting the "H24 Senior app", the task completion success rate was measured by evaluating if the user completed each task with or without help from the moderator, to assure the continuity and conclusion of the test.

Usability test tasks	Use case	Success rate
Create user profile	Use case 1	20%
Interpret care plan view (dashboard)	Use case 2	50%
Interpret monitoring view (dashboard) – use case 2	Use case 2	50%
Respond to humor notification	Use case 2	90%
Interpret data visualization: A/B testing of the chart	Use case 3	40% (chart A) 100% (chart B)
Interpret summary of my condition	Use case 3	100%
Respond to the phone call recommendations	Use case 3	90%
Comment and possibly share the assessment results	Use case 3	90%
Evaluate the quality of care	Use case 3	90%
Interpret timeline view	Use case 4	100%
Interpret chart evolution view	Use case 4	80%
User feedback on self-assessment	Use case 5	90%
Access to related health educational material	Use case 5	100%
Insert weight measurement	Use case 6	60%
Monitor heartbeat	Use case 6	90%
Interpret call scheduling	Use case 7	100%
Enable data sharing	Use case 8	90%

Table 5: Total of participants who completed each task successfuly represented in percentage.

The task completion success rate is presented in Table 5. According to the results, the less successful tasks were the ones that required interpreting the visualisation of more complex graphical data in the interface, such as the interpretation of data visualisation of chart A with 40%. Tasks related with simple graphical data, displaying a more linear reading e.g., interpretation of the "summary of my condition" were the most successful ones.

The most frequent errors are represented in Table 6 and show where they occurred and the number of occurrences per error.

Error description	Task	Occurrences
Difficulty taking and submitting a photo in the iPad	1.1	2
Confusion between the back arrow button and the next button.	1.1	4
Difficulty using arrows component to choose a number	1.1	3
Difficulty in submitting the date of birth using a calendar	1.1	1
Confusion between icons and input field	1.1 / 6.2	6
Tried to respond to a static list (regarding the future follow-up calls plan)	2.1	1
Difficulty in interpreting chart A (mostly associating the rings with its legends)	2.1 / 3.1	4
Confusion in the print button	3.2	1
Submit comment before its writing	3.2	1
Did not understand that the comments were about the assessment results	3.2	1
Wrong click on a date of a parameter in the evolution chart to access details	4.2	5
Difficulty interpreting the "+" button to add a new measurement	6.2	4
Confusion on the quality evaluation scores, assigned to the calls	7.1	1
Thought asking for change indicated nurse change instead of the call date.	7.1	1

Table 6: Most frequent usability errors during the tests.

5.8.3.10. Post-questionary test

The post-questionnaire (see Appendix I) evaluated the overall user experience and satisfaction of the application, combining the UEQ scale (User Experience Questionnaire) with 7 final questions to assess the user satisfaction and program awareness. The UEQ applies a specific questionnaire by addressing 26 items in a scale from -3 (most negative) to +3 (most positive).

The 7 final questions that also complemented the post-questionnaire, were assessed on a Likert scale, from 1 (strongly disagree) to 7 (strongly agree). Of these last 7 questions, 4 followed the System Usability Scale (SUS) and 3 were personalised and focused more on the application domain (impact on the health and wellness of the senior) and context (understanding of the program by the participants).

All evaluated items from the UEQ, showed a very optimal impression (with value near +2) about the user experience of the application (see Figure 72). According to the framework, our proposal reflects hedonic quality (stimulation, originality) with a score of 2,50, over pragmatic quality (perspicuity, efficiency, dependability) with a score of 1,70 (see Figure 73). Moreover, the attractiveness group also revealed a very optimal impression with a score of 2,40. Perspicuity was the item with the lower score, tough also with positive feedback.

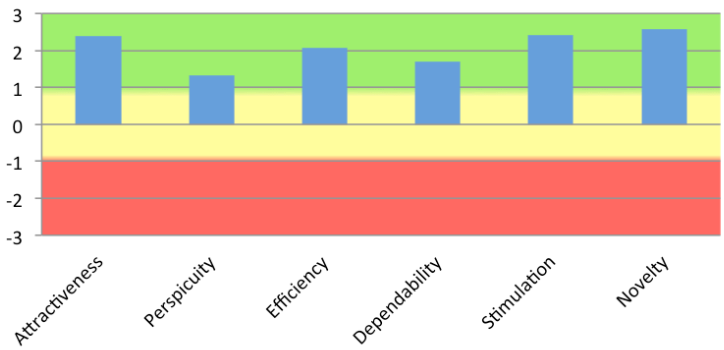


Figure 72: Evaluation results of the six domains of UEQ tool.

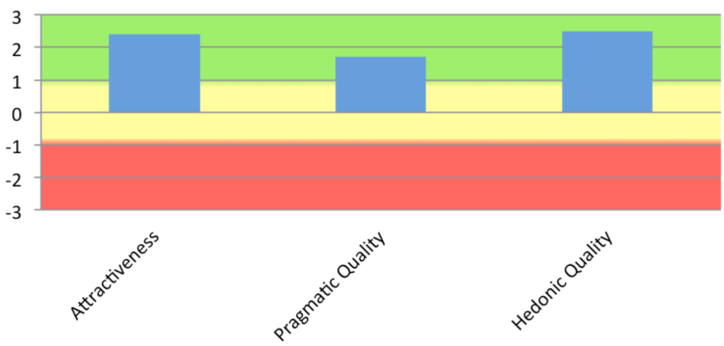


Figure 73: Mean of the 3 pragmatic and hedonic quality aspects of UEQ tool.

Final questions about the telehealth program context and application wellness domain showed that: the application increased the awareness of the users on how the service works and clarified its benefits; the application helps to increase the perception of the users about their integrated healthcare condition; users considered that using the application could increase their confidence about their health and support their wellbeing. These results can be seen in Figure 74.

Final questions about the user satisfaction showed that most of the users are independent when using the application; they would like to use the system frequently, except for two users; they found the various functions in the system were well integrated; and despite some divide, most of the users imagine that most people would learn to use the system quickly. These results can be seen in Figure 75.

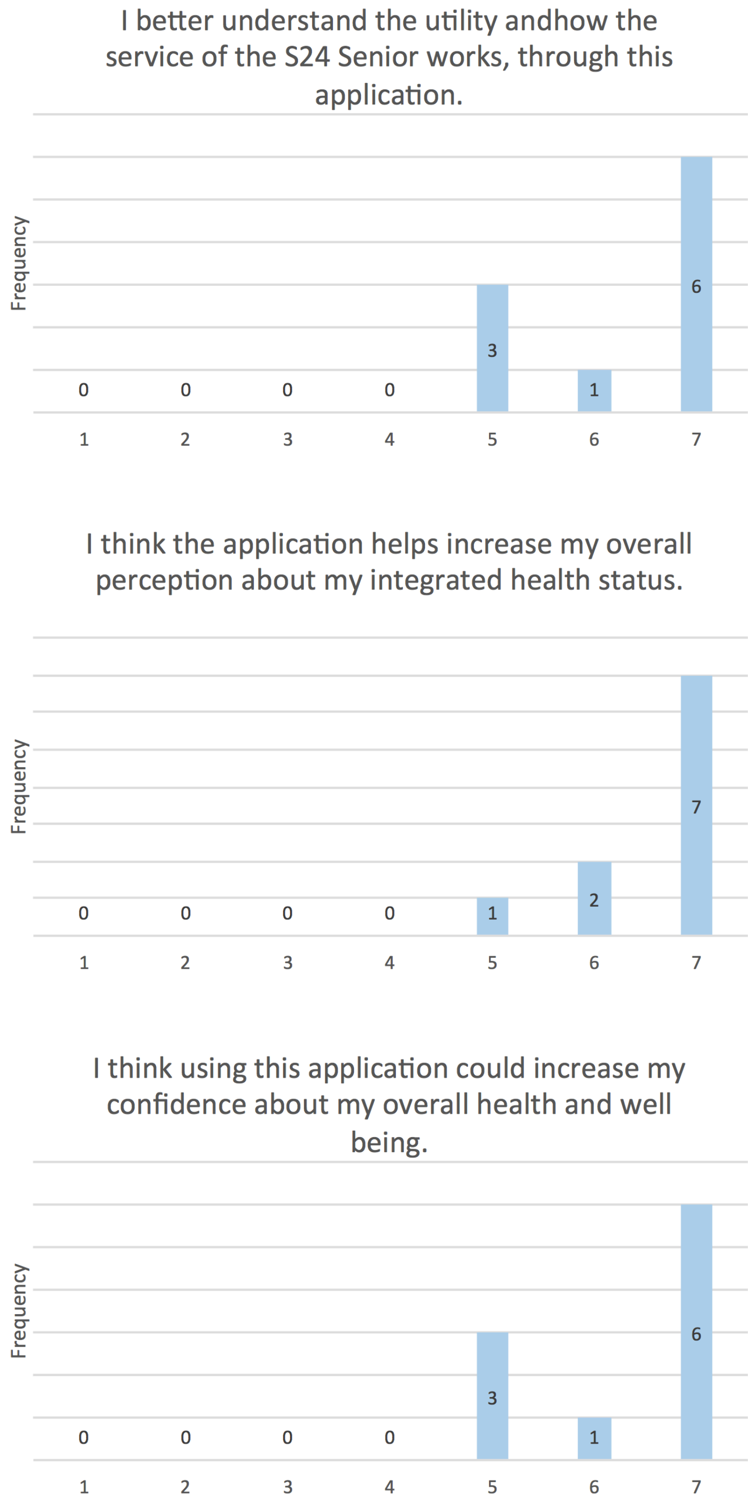


Figure 74: Histogram of responses to post-questionnaire focused on the application context and domain.

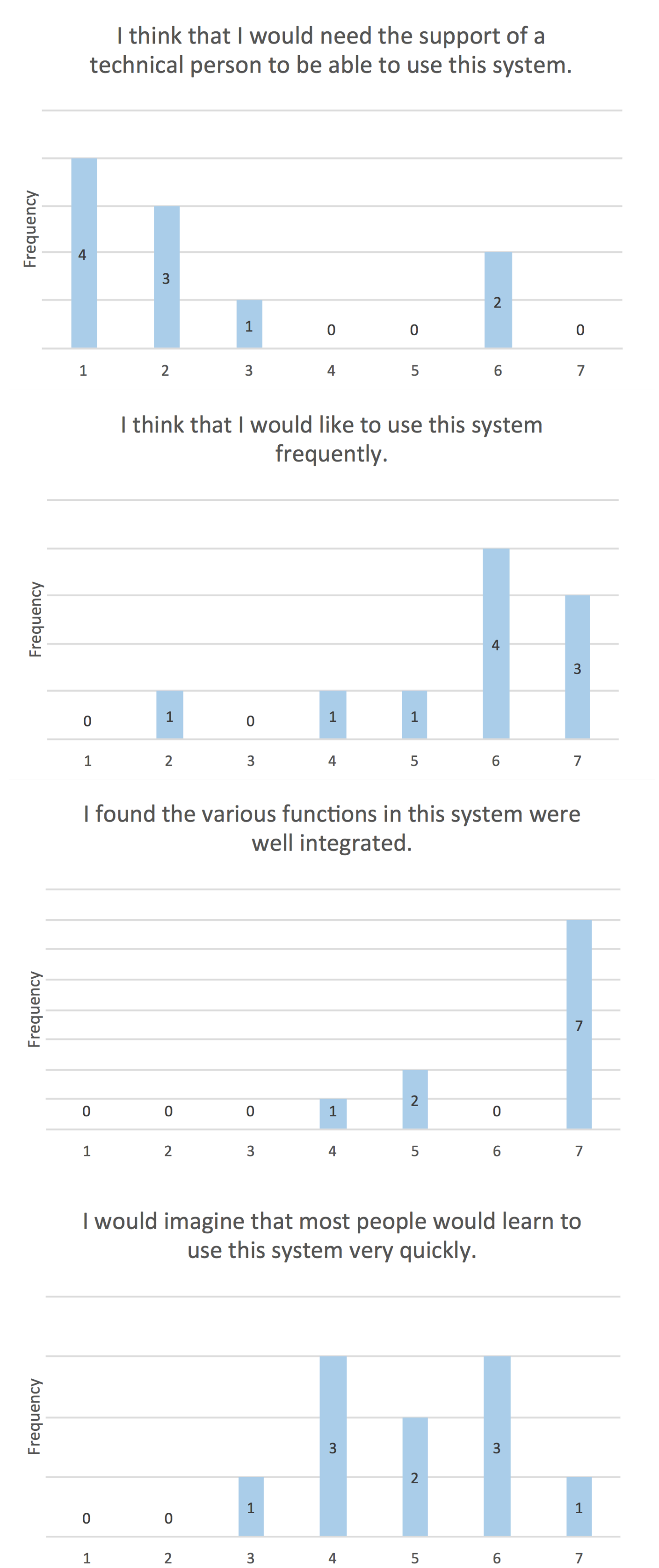


Figure 75: Histograms of responses to post-questionnaire focused on the application user satisfaction.

5.9. Results

Helping senior people to age in place, living independently and with comfort, led this research work to discover what can motivate them to contribute to their own wellbeing. Reflection, behavioural analytics and personal feedback are three baselines that are considered to play an important role in technology-supported efforts that sustain the individual self-awareness [21]. The design and development of a complementary web channel that applied an Integrated PHR named as "H24 Senior app" to the current phone-line of the Portuguese Nationwide Senior Telehealth Program, was inspired by these baselines. The research work followed a collaborative and multidisciplinary approach both with seniors and providers from the program, where several methods based mainly on qualitative, generative and field research, were applied.

User research began with a qualitative study that gathered the perspectives from the several intervenient groups of the service (nurses, physicians, program manager and seniors) about how a web channel could benefit the outcomes of the phone calls follow-up care model. Accordingly, participants from the study were asked about what were the major concerns in the current service, focusing on communication issues by phone, and if adopting a complementary web-channel could be of their interest, according to the needs of each group. This first study revealed the following main findings:

> For seniors, the impact of the program plays mainly a psychological role, reporting high motivation level in its enrolment (71,4% scored 5 in 1-5 scale).

> Both nurses and seniors expressed the need for having a more personalised care because currently the service calls were very standardised.

> Every senior wished to have access to their results and recommendations online, in a secure way and were willing to perform online self-assessments.

> Nurses and physicians explained that phone calls help to maintain an active conversation with the seniors, important to avoid loneliness, while the web could better engage them through a more continuous follow-up care model.

> The web was considered to enrich patient data by monitoring daily events (mainly at the emotional level), informing providers on how seniors are addressing recommendations.

> All seniors wished to visualise and interact with their Individual Care Plans (ICPs) over the web. While physicians suggested that visual feedback about their assessments could be very helpful to them, the nurses and the program manager advised that the data should be carefully displayed, only reinforcing their positive side.

> Seniors showed interest in having access to self-monitoring tools and health educational material.

Aside the user requirements that were collected from the findings that derived from this study, contextual inquiries and participatory design methods also took part of the research work, validating findings from the interviews and also involving physicians and people form the nursing staff in the design process of the "H24 Senior app". Information was collected about the ongoing work processes of the service, analysing the follow up care model, how the MAB tool was adapted to a phone-line telehealth environment and how the service was being supported through an existing software system in LCS.

The analysis of the software which was made through a contextual inquiry, has revealed a limited usage by the nurses, lacking several features that would benefit the outcomes of having a more user-friendly platform. This could be accomplished by enabling health comparison features to track how the senior is evolving over time according to the MAB tool, "handoff" features so that nurses could better follow the seniors randomly, and also seamless integration with other systems such as enabling an easy access to the events history from the NHS or basic health information about the person such as medication or allergies.

As first conclusion, the reported findings of the user research stage, highlight aspects that need to be addressed in the design of future Integrated PHR systems for telehealth environments focused on the senior community. The three main aspects related to the information and communication of the system are: usefulness, adequacy and collaboration.

Information provided by nurses to seniors is only useful if acted upon. Seniors frequently forget recommendations, and do not employ any strategy to prevent this from happening. An integrated PHR needs to have adequate reminding mechanisms so that the overall result is more than having regular assessments, and can move to a prevention program with verifiable long-term effects. The online channel could be a way for both seniors and nurses to provide feedback on how recommendations are applied.

To improve the efficacy of the program, information should be tailored to the senior as much as possible. This applies not only to the questionnaires currently applied through the phone channel, but also to other content that might be distributed through the online channel. Furthermore, it also applies on moving the service towards a more personalised care model that can be offered with the Integrated PHR. For example, by enabling senior profiling, useful information can be provided to the nurses about the context where the senior lives (what is their socio-economic status, family support, special needs, home conditions) and the way they would like to be treated during the calls for a more close contact. Still, there are other ways to improve efficacy and other qualities of service. Consistency, should be strived for in all dimensions, even consistency in the person that contacts the same senior. When this is not possible, the system should provide "handoff" features to the nurses such as a quick overview of the senior's history and condition to avoid the need to collect the same information. Having a consistent system also means to provide seamless integration with other systems to merge health data from multiple sources that stands for the nature of an Integrated PHR model.

The online channel can enable collaboration between stakeholders to explore the increase in available data (which in this research work only contemplated the senior profile for the prototype development). The two most obvious ways are: 1) giving seniors the possibility to "validate" some of the information nurses collect about after a phone call; and 2) give nurses the ability to validate in phone calls self-reports provided by the seniors between phone calls through the online channel with the Integrated PHR.

By the end of this use case, usability testing was conducted with a sample of current and potential users of the Integrated PHR to assess the user experience of the prototype that was developed for this purpose. Findings of the tests help to identify opportunities for the design of integrated tools to be used by senior people that may promote their wellbeing while influencing self-awareness over their health, in a holistic way. In this use case particularly, the exploratory features and integrated tools, took place on a telehealth environment. These digital tools play an important role by delivering in senior's home, a more complete service through a cross-channel user experience that enhances collaboration and communication with their providers. Lessons learned about the usability findings will now be described in the following sections.

5.9.1. Learning curve of H24 Senior app

The interaction with the tablet device was natural and well accomplished: participants navigated easily through the tasks, without much help even though half had never used tablets before. Those ones adapted quickly to the gestural interface, including the participant who did not use computers or another participant who suffered from tremor in his hands. However, it was observed during the tests that the higher the age of a participant, the greater the fear of making mistakes during the interaction with the application. One of the participants repeatedly asked during the test "Do I have to leave?" (referring to the log out button of the app, each time a new task was presented). For that reason, we noticed how important it is to design with clear undo or "back" options for this target group.

In general, there was great difficulty for seniors to abstract themselves from the simulated data. Even in case of the "Last Global Health Assessment" (the only feature displayed with real data), participants showed a clear tendency to describe how they felt and what were their current problems, instead of interpreting objectively the data. We found that designing with a clear focus and performing usability testing with real data is important to stimulate the attention of senior people, during the execution of the tasks.

5.9.2. How holistic assessments can be displayed to seniors

According to the visualisation techniques explored (which were considered to be appealing by the participants), we concluded that the interpretation of more complex graphical UI data, such as charts and dashboards, increases the cognitive load of the senior, in contrast with UIs that display a more linear reading. However, we showed that it is possible to design comprehensible charts. Chart B from the A/B testing proposal, was well interpreted by all participants allowing them to have a full picture about their wellness dimensions in an attractive, quick and holistic way: "You already perceive my spirit because you see me as a whole". We believe this chart model can be helpful in the design of other applications displaying geriatric assessment results to seniors.

Self-perception, a parameter we decided to highlight separately from the MAB tool to further test self-awareness on how seniors see themselves compared to how others evaluate them, was well interpreted and considered to be relevant information. Interestingly, participants showed a clear tendency to compare their wellbeing with their friends or people of the same age, also seen in other studies [192], which suggests that this metric might be relevant to contribute to the individual self-determination, having consequently a positive impact on their wellbeing (this metric can be sustained in Self-determination theory" (SDT) [21] described in Section 2.6).

5.9.3. Self-assessments as an empowerment tool

Regarding self-assessments, all participants expressed the desire to understand their own wellness information more in depth and considered it to be rewarding. Besides becoming aware of their wellbeing, they considered the digital channel to be a more private way to answer more sensitive questions about their condition. Accordingly, people are more willing to disclose information about themselves (specially regarding health issues) in an online interaction than they are face-to-face [110], or in this case, rather than by phone. Furthermore, they also saw the potential of avoiding unnecessary medical appointments, understanding better the benefits of being enrolled in a telehealth program. Nevertheless, some participants made remarks about some questions and given results, which they found to be misfit to their context. We found that tailoring information and studying more personalized interfaces in geriatric assessments may require further research.

Content that summarizes their health condition needs careful attention, especially when it assumes the person is feeling well. Related educational material after the results displayed during the tests, was one of the most wanted features among the participants. Getting to know more about good life habits or being able to access healthcare counseling (e.g., fall prevention), was especially valued by women.

5.9.4. Reflections on engagement and gamification features

In terms of reflecting on their integrated health evolution, we concluded that the most isolated, the most emotionally vulnerable and the elderly, are less interested in knowing about their evolution, over time. On the other hand, the most active ones are receptive to monitor their evolution (more on a weekly rather than a daily basis), even when the results are less positive. This group also showed a greater interest in integrating sensors, such as a smartwatch, for monitoring their lifestyle. Findings also suggest, in accordance to prior research [28], that developing sensor device that reduce or eliminate the exertion required for collection of observations of daily living can be a benefit, especially for this target group. The same applies on joining the suggested competition game in the application that we called "H24 Senior Records". According to the tests, older participants are less encouraged in engaging with gamification design features. Once again, the most active ones shared their interest on being compared with their peers on a positive competition. Furthermore, several suggested increasing the communication in this feature by allowing the people from the program to connect. Some of the participants have shared that they already used their computers or tablets to play games regularly: "I play a lot on the iPad" or "I am addicted to games". This shows that gamification features can be a way of engaging the seniors in the use of Integrated PHRs, which has the potential to be explored in future studies.

5.9.5. Evolving the program to a cross-channel user experience

The opportunity to establish daily goals in phone calls was well accepted by the majority of the participants. However, when it comes to monitor the goals on a daily basis, through the application, the majority did not want to assume such a commitment, despite finding it useful for their physical activity. It was also observed that presenting photographs of the nurses who perform the phone calls, added value for the users, helping to generate greater empathy in the enrolment of a telehealth environment. All participants were receptive and showed interest in providing feedback to the program through several features such as responding to the phone call recommendations or comment an assessment given by a nurse. It was generally acknowledged that with 'H24 Senior app', people could feel they are part of the process, understanding better the service experience. To those who were not part of the program (participants from group B), despite an additional brief context explanation about the program *Saúde 24 Sénior,* was provided to them before the begining of the test, it was possible to validate part of the user flow displayed in Figure 43, which represents the registration process for first time users of the program. After responding to the senior profilling stage, participants successfully performed a GHA and interpreted correctly the ICP results, before a previous contact with the nurses from the service was made. According to their feedback becoming aware of their wellness state through the application, worked as a motivation to join the program. Also, it was also possible to validate by the end of the tests that they could perceive how the service works.

When asked about, these participants have reported that they wanted to join the program in an integrated way (phone and web), except for one who mentioned he would "leave it for the future in case of autonomy loss". Nevertheless, another participant of group B, expressed several times that she wanted the application to be already installed in her tablet, which is a promising indicator for the adoption of the presented proposal by the seniors, both current and potential ones, which can be extended to other similar efforts.

Conclusion

This dissertation has demonstrated throughout the analysis and development of two use cases, in cooperation with two organizations (LCS and SPMS) connected to the Portuguese Ministry of Health, how an Integrated PHR can be a powerful personal tool, to be used by the citizen with undeniable value to the demands of an aging society.

The main motivations of this thesis were presented in Chapter 1, which can be summarized as: (1) the design and adoption of Integrated PHRs to answer multiple needs in the healthcare sector such as gaps in effective communication amongst providers that compromise patient safety, together with problems raised by a poorly integration of systems that affects team care coordination; (2) the design of digital user experiences focused on senior people, as the user group with highest potential of adopting this new type of systems, understanding what are their particular needs; (3) the setting of an Integrated PHR within a senior telehealth environment, enabling health services in the person's home with the goal of improving care delivery, helping people to age in place.

By analyzing the trends of personal healthcare informatics and human needs, the work of this research applied a user experience design methodology focused on design strategy, leading to the development of two prototypes. In order to engage the citizens to reflect about their healthcare and wellbeing, the design strategy that sustained the foundations of the PHR design model, can be outlined according to a stage-based model of personal informatics systems [100] which consists on preparing, collecting, integrating, reflecting and acting upon oneself self-collected data, which naturally contributes to self-knowledge and behavior change.

The engagement of the stakeholders during the two use case studies was accomplished with participatory design methods and followed a multidisciplinary approach to create solutions that would meet the human, politics and behavior interdependencies, which were part of both projects. These have shown to be inherent aspects to have in consideration, in the design and implementation of new technologies in healthcare settings [41, 175] [55], which were felt along the several work stages of this research.

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The first use case from **Part 1**, responded to **RQ1** *"How can we combine and represent health data from different sources, into Integrated Personal Health Records to improve the user experience of the citizen healthcare?"* which addresses the identification and design of features meaningful to populate the Integrated PHR. The proposal that was created derived from an extensive literature review that can be found in Section 2.8.

The user research stage consisted on five studies (combining qualitative with quantitative methods) conducted to first evaluate the state of the National Patient Portal beta version and then to inform the creation of a new solution, based on real data from the users of the platform and also on stakeholders inputs. The design model proposal and prototype that resulted from the findings of user research had very meaningful results that were discussed in Section 4.7.

Among the results, the first part of this thesis has left an important contribution for other studies that contemplate the design of an Integrated PHR. The extensive literature review by itself is a reliable resource that can inform the functional analysis of the system. Researchers can benefit from the review by selecting, among the provided list, the features that fit the needs of their research context, when creating the PHR.

The Participatory Expert Review (Section 4.4.1) conducted in the beginning of this case study, left a set of heuristics (gathered from different references), which were found to be appropriate to evaluate healthcare applications. These can be used in a general sense by other studies of this same domain. Moreover, it also showed how important is to include reviewers from multiple domains, putting healthcare providers together with developers, when evaluating the design and implementation of healthcare applications.

The other provided resource is the information architecture, which was validated by a significant audience of users, with the goal of understanding and comparing mental models of younger versus older people and lay people versus healthcare providers. Interesting to know, according to the conducted card sorting method (Section 4.4.2), was that despite the digital divide that typically distinguishes the use of technology by senior and younger people, their mental models are very similar and consistent. This may be an indicator that when the use of technology by the seniors fails, the reason does not rely on their way of thinking. Naturally they may differ, for instance, if both groups are from different socio-economic status and cultural background. Still, usability problems are probably the most plausible explanation for this divide, which includes the organization of content. According to this view, perhaps guidelines for senior people should mainly make sure that the use experience of a digital product is following good design. According to the "Design for all" philosophy, the design for older people happens to work better for everyone: "design with older people in mind can be multigenerational, inclusive, universal and in every sense better design" [167].

On the other hand, healthcare professionals understood eHealth features mainly on a "sharing data" perspective compared to lay people that understood them on a "managing data" perspective. Previous research has suggested the need to detail how mental models from these two user groups could be reflected in the PHR information architecture [89, 207]. According to the results from this research, the dichotomy that was found between "sharing the data" by the providers and "managing the data" by the patients, suggests that these perspectives should be reflected in the design of the user tasks in both user profiles, in a way that can foster the patient-provider relationship within the platform.

Interviews from different domains conducted with the stakeholders of the portal, including project managers, developers, people from customer support and communication strategy, contributed with lessons learned about what has been the experience of implementing a Nationwide integrated healthcare platform, focusing in this use case study, on the Patient Portal.

The results of the interviews (Section 4.4.4) contributed to the analysis of several topics, to provide directions for the improvement of the portal. Privacy concerns were actively discussed among the project team. Ideas for building trust among the users were shared by the several interviewers. One of the main limitations that were mentioned was the lack of awareness that the Portuguese citizens had about the potential benefits of the portal usefulness, which was not clear at the time. When accessing the portal, users could not understand the overall cross-channel user experience of the portal, within the PDS ecosystem. This means, among other reasons that were identified during the study, that the Integrated PHR had a very limited usage. Users were not aware that professionals could access their data. Furthermore, self-tracking tools were not yet very popular among them. Only eHealth features such as scheduling appointments online were used.

As an example relevant to mention in this conclusion, this issue was addressed during the method of backcasting when together in this research, the team identified as a possible future ideal scenario, integrating all portals of the PDS (patient, professional, institutional and international) in a consistent and unique entry of the platform's public area (before the login). This solution was launched in February 2016. According to their role, users can now enter the system by selecting their area. An intermediate version addressing the other three ideal scenarios from backcasting, also drastically improved the number of new registrations of the platform in a middle stage (Section 4.7). Making the portal and the PDS more visible to the citizen, improving user awareness was an important achievement of this work.

Another outcome from the first part of this thesis is the definition of the diversity of user groups that can be enrolled in the user experience of these platforms. The way these groups were created, based on a real online behavior from the Portuguese citizens that were using the portal, is a valuable resource to be used by researchers who are addressing the roles of patients in their self-care [8, 190]. Not only current users but also potential ones were provided, grouped by their affinity and engagement level and supported by personas (Section 4.4.6). Also, as this use case covers a wide spectrum of users, they can easily be applied in the design of any Integrated PHR. Nevertheless, it would be interesting in further studies, to confirm and explore the diversity of users that were identified in this research work. Interestingly, women are the most typical users of the portal. This stands accordingly with literature that shows the importance of the women role on the family health management [20].

As recommended by the European eHealth network [53], the design model proposal of this use case study (Section 4.5), can contribute with the delivered outcomes, to the promotion of good practices, to the other European Nations that are also building integrated healthcare networks similar to the PDS in Portugal. Moreover, it can also serve as an inspiration to PHRs locally deployed, as long as they merge data from providers and patients in a perspective of collaborative care. While the application structure provides a general overview of the information architecture and main navigation, the user interface design details the information, interaction and design specifications that can serve as inspiration to other studies that wish to apply the model.

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The second use case from **Part 2**, responded to **RQ2** *"Which PHR features are most effective in improving healthcare outcomes in senior people?"* and **RQ3** *"How can we create a valuable user experience that may enhance the senior's healthcare self-awareness, while simultaneously engage them to work together with their providers towards the achievement of their wellbeing?"*. While the main goal of the second question was to identify the most suitable PHR features to senior users, the third question was more focused on the user experience of using these tools, through patient-provider collaboration, in a way that could benefit the senior wellbeing. The design of a PHR to be integrated in a telehealth environment, also with large nationwide impact (the Portuguese senior community), combining phone, web and a smartwatch device, allowed this research to collect and analyze meaningful data to answer these questions and also to provide additional insights that were brought by the specificity of the case study.

The proposal that was created named as "H24 Senior app" intended to complement the current telehealth service (Saúde 24 Sénior) and was a result of a close collaboration with a clinical team that included nurses and physicians, as well as with a sample of seniors whom, in their majority, were enrolled in the program. The starting point of the proposal was based on the design model from Part 1 and can be found in Section 4.5. From that point on, four user research studies based mainly on qualitative, generative and field research, were conducted to collect the design requirements, validate the prototype development with the participants of the clinical team, and evaluate with the seniors the user experience of the final solution. An enriched discussion about the results of this use case is provided in Section 5.5.1.13.

To highlight some of the results accomplished in the second part of this thesis, the presented work produced evidence on the desirability of adopting an Integrated PHR within a telehealth environment. Both the perspectives of seniors and clinical stakeholders were addressed and compared, having been shared the benefits and hurdles of the service. The provided findings can inform other studies that address the perspectives of seniors over the usefulness of PHRs [148].

The possibility of engaging with an Integrated PHR, was well accepted by both parties that contributed with design specifications inputs for the solution. The fact that this research has interacted with the several participant groups from the program during the design cycle process provides a grounded overview of the way a telehealth program is created and supported by the clinical practice. Then, it shows how the program can be improved with a digital channel in order to meet the expectations of their participants.

Several guidelines were provided about the usefulness, adequacy and collaboration regarding the design of future Integrated PHR systems for telehealth environments focused on the senior community. Perhaps the most important to state, is the advantage that an Integrated PHR can offer, by moving the service towards a more personalized and continuous follow up care model. As an example, enabling more contextual data about the seniors to the nurses that follow them (e.g., know if they have any family support); providing additional personal data through manual or automated health measurements between the phone calls to understand their progress or trigger critical events; and enabling a way for seniors to give feedback on how they are handling recommendations or ask questions about their care plans, proved to be essential contributions of the web channel, to enhance the user experience of the service.

Despite usability needs for senior people were considered during the design and evaluation of the prototype, the most important results from this use case study, come from considering the methods that were used to analyze, adapt and innovate the delivery care model of the service into the PHR. These have provided ways to map and apply MAB, an assessment tool used by the program (Section 5.3) that addresses the bio-psycho-social wellbeing of the senior, in a patient-centered perspective. This work provided an innovative way to convert this geriatric tool into a digital tool for performing wellness self-assessments. Moreover, the user interface that was designed, also shows a way of integrating this tool with the goals of the service, associating, for example, the last ongoing assessment with the corresponding sub-sequent evaluation calls, the nurses who perform those calls and the recommendations that were provided. Another strength is the ability to represent the senior wellbeing over time through a timeline, enabling the users to reflect on their progress, in each of their healthcare domains. This tool is an important contribution from this research, which can be useful to other work that addresses holistic self-tracking tools to evaluate the person according to a whole [47] [192].

The evaluation of the prototype showed how seniors were interested on visualizing in an integrated way, the several dimensions that together, reflect their wellbeing. Visualization techniques were explored and gave very positive results that can inspire other work that addresses the complexity of healthcare data visualization. Enabling self-assessments to seniors was felt as an empowerment tool. Besides considering it to be rewarding, participants expressed how it could be a more private way for them to respond to more sensitive questions rather than by phone, and how it could help to avoid unnecessary medical appointments.

Becoming aware of their wellbeing in a quick way through a digital tool was considered to be a valuable asset, even more if it connects with educational material that informs how to improve lower health results of the assessment. The possibility of questioning the assessments made by the nurses was, likewise, valued by the participants. This suggests their will to be in control of their data and participate actively in their healthcare. This can answer questions raised by previous studies that aim to understand how far seniors wish to participate in the healthcare decision making process [220] [165] [36].

However, important findings from this research also indicate that further studies can be done to adapt the display of geriatric assessments to seniors. Content that summarizes their health condition can be hard for users to accept, especially if it assumes the person is feeling well. Once again, the more personalized the tool becomes (providing ways to assess the person's context awareness), the more users become confortable in using the tool.

Another conclusion that stands out is about the concerns raised by self-tracking tools that involve sensor devices, gamification features or long-term self-reflection features such as the case of timelines. According to the results, they were not very well accepted by the elderly seniors or by people who were more vulnerable. Possibly due to an older age (there were several participants above their eighty years old) and also due to a lack of interest of the most isolated, this type of tools seemed to increase their anxiety. On the other side, "younger seniors" felt motivated on using these features probably because they have a more active lifestyle that compels them to be more open to experiences of this kind. Perhaps these experiences, which may be considered more advanced, should follow a more balanced approach when delivered to senior people. These findings help to inform related work that have suggested the need for researching about which motivational aspects may influence senior people to use monitoring devices [132], studying their behavior and needs [8].

To conclude, this dissertation reported the process of working with healthcare organizations that depend on governmental policies and clinical management decisions. This type of collaborative dependencies on teamwork can be quite a challenge for researchers.

At this stage, it is possible to assert that the applied UX methods, helped stakeholders (mainly developers and project managers) from the Portuguese Nationwide Patient Portal with an integrated PHR at its core, to understand the diversity of users that take part of such a large ecosystem, also allowing them to share their lessons learned. Furthermore, the study of the corresponding platform enhanced the potentiality of exploring the benefits of the emerging Integrated PHR model. As a result, the design strategy for Integrated PHRs in this thesis was based on combining real data from this pilot project, with research directions given by the scientific community over this topic.

On the other hand, the second part of this thesis, demonstrated how the foundational design model that derived from the first part, can be easily applied in another healthcare network environment, enhancing the delivery care model of a Nationwide telehealth service that aims to avoid social isolation among senior people. The design strategy in here was to delve more in the exploration of PHR features focused particularly, on this user group. In its turn, the conducted UX methods in this use case helped the stakeholders of the service (mainly healthcare providers) to envision how the assessment of the senior wellbeing and its inherent dimensions of autonomy, social and health, can be improved through engaging digital tools, adapting the clinical practice to a digital and pervasive world.

Future work

Wellbeing-driven improvements to digital experiences have the unique potential to effect population-wide positive change.

Rafael Calvo and Dorian Peters, in "Positive Computing"

In a future ideal scenario, the proposals that derived from both the studies in this thesis would become integrated. After all, that is the purpose of Integrated PHRs. Nevertheless, as it was already mentioned before, when the research has to dig in the political and organizational boundaries (which in this case are part of the healthcare sector), bridges must be build to positively impact the current state of the world. Also, as previously discussed, innovation in this context can only be achieved with the cooperation of the stakeholders who need to be persuaded on following scientific trends. The reason for creating two different proposals, relies on the fact that despite both collaborations were agreed with the Portuguese Ministry of Health, the projects were ran by different institutions, independent from each other. If not the case, the Integrated PHR would probably be the same, as the users they have in common, could be the same (seniors from the telehealth service can also be users of the Patient Portal). Nevertheless, as one derived from the other, they can easily be merged. Furthermore, while following the same structure, the other possibility would be to migrate the data from one system into the other, if the solutions become implemented in the future. Towards this more ambitious future ideal scenario, it would be highly convenient to enable the developed wellness assessments based on MAB tool from the telehealth program (Saúde 24 Sénior), in the Portuguese Data Sharing Platform (PDS). This applies to both the citizen and healthcare providers who should be able to access the assessments in their respective portals and be able to share them during clinical appointments.

As a remark, the prototype from the first use case regarding the National Patient Portal, could benefit from future usability testing to validate the user experience of the proposal, even tough it was sustained on an extensive literature review and several user research studies. However, it is important to assert that the Integrated PHR design model that results from this thesis, is transversal to both use cases that were explored in this dissertation. For this reason, the design model that derived from Part I, was then applied and tested, in Part II.

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Indeed, the work that was presented in this dissertation requires further research to allow Integrated PHRs to flourish in the design for personal healthcare sustainability.

Recent literature reviews about the evolution and adoption of Integrated Personal Health Records [8, 226] [61, 160] still indicate that despite that patients embrace the idea of Integrated PHRs, its adoption has been low as patients remain unaware of its benefits and features, also confirming the results presented in this work. Moreover, they indicate that there is lack of consensus on what information to include in an Integrated PHR due to lack of involvement of patients and providers in the design process. Likewise, privacy and security concerns currently remain as the most sensitive aspects to address in the design and development of these systems. Also, the reviews refer that the current solutions that are offered, do not provide patients with all possible capabilities.

While the outcomes from this thesis may contribute to the efforts of bringing consensus, showing opportunities to design Integrated PHRs, there is still a long way to go, in order to have these systems globally spread, implemented and used by the citizens. Naturally, the way this model will continue to be adopted in the future will depend on the type of healthcare system and its related policies that one Nation offers to their citizen. Does it rely on a private, closed healthcare system or does it rely on a public one? As we have seen in Part I of this dissertation, a public healthcare system can more easily share data, as a nationwide healthcare network can facilitate the sharing of data across several institutions, offering possibilities for the Integrated PHR to be used. On the other hand, if it depends on a private healthcare system, such as the case of the US (based on health insurances), this model may face more challenges towards integrating and sharing the data of the citizen across different type of facilities throughout the country, as they are independent from each other and not connected. Moreover, one Nation can offer both systems, public and private, giving the citizen the possibility to resort to both, which also happens in Portugal and other European countries.

In any case, the model is prepared to combine both, either private or public, as long as healthcare organizations are willing to change their practices by recognizing the benefits of the Integrated PHR. Only then, it will make sense for the citizens to adopt the model as they depended on the established practices of the provider side.

Several research directions can be given from the results and discussions that were presented throughout this dissertation. In a broad sense, some of the prospects are similar to previous studies regarding the use of PHRs that were reported in literature review, in Section 2.4. As an example, it would be important to study how health information from different medical specialties can be more easily correlated and enhanced with the inputs of the patients [79] [127]. These include the typical features that characterize PHRs, either manual or sensor based, which are expected to evolve throughout the years, in the categories identified in this thesis of electronic healthcare services, patient education, self-monitoring tools, information sharing and patient decision support.

Healthcare providers value different types of information and expect it to be displayed in ways to support knowledge discovery, such as visually "map out" content connections. To accomplish this vision, ways of crossing data, such as multidimensional diagnosis, need to be studied. Data visualization techniques and user interface design plays an important role in here, by exploring ways to identify health behavior trends. This is particularly meaningful to provide a global understanding of the individual and also to detect the origin of health problems.

The way the clinical practice behaves today, does not always assure that people get the proper diagnosis in a clinical visit, for example, when communication breakdowns occur during handoffs in healthcare institutions [70]. This does not rely only upon the hard task that providers face when dealing with complex situations, but also on the workflow process they have to follow while working in healthcare institutions. On the other hand, institutions depend on computers and how they behave to support humans in their tasks. As such, as both humans and machines may fail and they often do, diagnosis are no exception to fail as well, uncoordinated care may happen, and the patient can be lost in procedures and administrative issues that delay the discovery of the right treatment. As already explained throughout this dissertation, senior people are usually the ones who are most affected by these transitions, as they are more susceptible to face multiple conditions at the same time, increasing the complexity of their need for care. Therefore, the design of healthcare technology has to follow the demands of human nature, even more in an increasingly aging society, which requires fast delivery care models.

To accomplish these models it is necessary to study the design of cross channel and omni-channel user experiences of the diversity of digital health solutions that are emerging today. While cross-channel strategies provide different means of engaging with an organization[25], which were explored in both the proposals of this thesis, omni-channel strategies are considered to be more holistic experiences as they explore the advantages of using multiple devices, according to the users context and needs, also breaking the gaps between the digital and physical world [168]. Omni strategies involve the transitions throughout the interaction with different channels that are offered in a seamless way with minimal overhead for the users. Users are allowed to pick up in one device, where they were left off in another. Likewise, the use of digital devices needs to be social as humans are. User experiences need to be designed for a networked world. Further studies on the design of Integrated PHRs may take these directions in consideration.

The complexity of designing this type of digital tools can be a challenging work but worth of future investigation, so that we can keep moving towards a strategy of coordinated care and collaborative reflection between patients and providers.

According to what was presented so far, what kinds of patient inputs are necessary to accomplish more integrated views? How can they be designed? One direction is to design for "organic Health IT" [115] which as explained before, means to create dynamic visualizations to allow patients and their clinical team members to explore and record the data in order to interpret it collaboratively.

Wellness diaries are potential features in the cycle of care that can be embodied in the Integrated PHR or used as third parties applications that can be connected with the system. Diaries enable ways of visualizing integrated data and reporting behavioral trends over time, giving the user the possibility to reflect on their data, detect the origin of a health problem and change their life habits. When shared with providers, actionable care plans can be more easily discussed together to treat a condition or to prevent critical episodes from happening. Among the existing consumer technological devices available today, i.e., smartphones, tablets, desktops, smartwatches and other wearables (e.g., Fitbit or Microsoft Band) probably the smartphones and smartwatches/wearables are the more promising ones to explore wellness diaries because of their regular use during the day and because of their sensing technology.

Mobile health shows promising opportunities for designing Integrated PHRs [160] [77]. The exploration of diaries in the scope of mobile health can combine quantitative with qualitative data by crossing physical and emotional tracking, with daily life habits, activities, events and experiences. For instance, assessing social interaction can be useful to detect a context of isolation that may lead to a depressive condition. Another example,

25 https://www.usability.gov/get-involved/blog/2013/11/creating-cross-channel-experiences.html

assessing daily activities can trigger an emotional response derived from an activity that may be affecting wellbeing. These assessments can be momentary and improved with sensor data of the person's context, which is invisible to the user: the accelerometer can detect physical activity, the Global Positioning System (GPS) can detect location, and the phone and SMS logs, i.e., text messaging can detect social activity [163]. The advantage of these sensors is its ongoing collection of data during the day, without interrupting the users in their daily activities. If used properly, they may contribute to detect the origin of a health problem or at least to identify in which context or under which conditions, the person is not feeling well.

Nevertheless, the use of the diary can be expanded to other devices, according to the goals of the application, taking advantage of the characteristics that are offered by each device, as result of the pervasive and ubiquitous world we live in. For example, applying a symptom diary to assess the person on a daily basis can be more confortable and quick to answer on a mobile. On the other hand, the use of a smartwatch, as a wearable device, can be more accurate to measure physical activity or the heartbeat of the person throughout the days, as users may not be always in the possession of a phone during the day. Later on, after a period of time as passed, the data that was collected from the several logs and sensor collection from the devices, can then be visualized together in a larger device, i.e., tablet or desktop computer to consult the evolution of the person over time. Moreover, larger devices may also be more appropriate to report self-assessments such as the MAB [58] used in this thesis for measuring the bio-psycho-social wellbeing of senior people, or the Satisfaction with Life Scale (SWLS) [45], used for measuring subjective wellbeing (this one extendable to different age groups). As a fact, people may find these assessments too long or intrusive (also depending on its frequency) if used in a mobile solution. Larger devices can also have the advantage of displaying and comparing data from different sources that can be displayed in more detail. Timelines are interesting components to correlate different types of data over time, which would be interesting to explore in user interfaces from future studies.

According to this journey map, users would be offered with omni-channel user experiences, as the use of several devices would serve each other at the same time but with different goals. Finally, as we are working with Integrated PHRs the idea would also be to enable simultaneously, the data that is being collected in real-time through these diaries, in the user profile of the providers. In this case, patient data could also be combined with treatment reports, annotated by the providers, also in timelines, dashboards or other components tailored to their needs.

Ongoing studies and recent innovative market solutions in the field of mobile health are already exploring diaries to support wellbeing, which can serve as an inspiration to take part of further investigation on Integrated PHRs.

By combining momentary assessments and sensor data, Emotion Sense is an application that studies the contextual factors related to daily fluctuations in mood, using smartphone-based experience sampling, sensing, and machine learning [163].

Life Cycle is a "behind-the scenes companion", requiring minimum manual input from the user [102]. It consists on an application that maps the life of the person. While developed for people who wish to understand where, and how they spend their time, it also crosses data with another app from the same family that tracks the sleep called Sleep Cycle, [176] suggesting the user to become aware of how their daily activities and locations may affect their quality of sleep.

PaintMyEmotions, is an interactive self-reflection instrument that allows individuals to assess, express and monitor their affective states in a fun and engaging way [126]. The emotion assessment interface proposed by the application explores artistic expression such as painting, photography and expressive writing to self-report emotions. The final goal is to improve emotional health and wellbeing, also taking advantage of mobile automatic collection of data (e.g., "you usually feel joy when you are at location X" or "You have reported mostly negative feelings when you are with person Y").

An important theme to have in consideration for future work in the design of Integrated PHRs is Positive Computing. Rafael Calvo and Dorian Peters have synthesized theory, knowledge and empirical methodologies from a variety of disciplines such as psychology, neuroscience, human-computer interaction and others, defining positive computing as the design and development of technology for supporting psychological wellbeing and human potential [21].

While contradictory it may seem, according to the authors, the use of digital technologies, pervasive tools and multiple devices, may increase stress in the human being and fail on serving its best for humankind. More contradictory it turns, if we think about the use of Integrated PHRs according to this view, as they are supposed to support citizen in the accomplishment of their good health. As such, studying wellbeing factors, which are proposed in the framework of Positive Computing, including positive emotions, self-awareness, mindfulness, empathy and compassion, are key directions to follow.

Finally, to complete the whole research of the user experience that sustains the Integrated PHR, it is necessary for future work to analyze and detail the provider side, as one does not make sense without the other. While this thesis was more focused on the patient side, as owners and primary beneficiaries of these systems, the provider side is inherently important as well to be investigated. More specifically, it is important to explore meaningful workflows on how the exchanged data can be interpreted collaboratively. Are providers willing to incorporate the data that derives from the PHR self-tracking tools into their workflow practices? How can this data become reliable enough, for providers to include it in their clinical assessments and care plans?

Also, on the other hand, it would also be meaningful to study how electronic medical records (EMR) should be displayed to the patients in the Integrated PHR. Although they were considered during this thesis, placed in the system structure of the Nationwide Patient Portal proposal as “unique summary care record” (see Section 4.5.1), and explored in the second use case of the telehealth program, concerning the access and interaction of the seniors with the MAB assessments enabled by the providers, an EMR is far more complex, as it should assemble in a summary, all the medical and treatment history of patients, from each medical specialty. Although some studies explore the usability and safety in EMR interface design by clinicians [223] or the perceptions and use of EMR by non-clinicians, concerning other professionals who work in healthcare environments such as social workers or administrative staff [124], there is a gap on studying the display of EMRs to the patients, which needs to apply comprehensive taxonomy to be used by lay people [96]. In this context, what are the best ways to design and display this medical integrated data to the patients, in a way that the EMR can be clear to the users, also preventing possible negative feelings that may derive from the access to more sensitive data reported by the providers?

Currently, there is still not a consensus about the definition of the term that concerns the model of the Integrated Personal Health Record. Despite that several studies addresses the term [226] [43], the model is often referenced as a Patient Portal (by this means an electronic personal health records tethered to institutional electronic health records [75]). Yet, this thesis suggests that the Integrated PHR is a broader definition, more patient-centered, crossing methodological boundaries between Health and HCI. Thus, this concept opens possibilities to use the system in any type of upcoming healthcare environment that may take place in the future, combining the physical world with digital experiences driven to improve the citizen wellbeing, ultimately making humans more able to take advantage of their full potential, while going through the threads of the tree of life.

References

[1] 10 Usability Heuristics for User Interface Design. http://www.nngroup.com/articles/ten-usability-heuristics/ Accessed: 2014-04-24.

[2] Adikari, S., McDonald, C. and Campbell, J. (2011). A design science framework for designing and assessing user experience. In: *Human-computer interaction. design and development approaches, 25-34*.

[3] Ahamed, S. I., Haque, M. M., Stamm, K., & Khan, A. J. (2007). Wellness assistant: a virtual wellness assistant using pervasive computing. In: *Proceedings of the 2007 ACM symposium on Applied computing* (pp. 782-787). ACM.

[4] Ahmed, M. and Ahamad, M. (2011). Protecting Health Information on Mobile Devices (2012), In: *Proceedings of the second ACM conference on Data and Application Security and Privacy*. ACM, p. 229-240.

[5] Al-Ubaydli, M. (2011). *Personal Health Records*. Wiley-Blackwell.

[6] All Together Now: Introducing the participatory expert review: *http://uxmag.com/articles/all-together-now*. Accessed: 2013-09-16.

[7] Alwan, M., Dalal, S., Mack, D., Kell, S.W., Turner, B., Leachtenauer, J. and Felder, R. 2006. Impact of monitoring technology in assisted living: outcome pilot. In: *IEEE Transactions on Information Technology in Biomedicine*. 10, (1), 192–198.

[8] Arch, A. Web accessibility for older users: successes and opportunities (keynote). (2009). In: *Proceedings of the 2009 International Cross-Disciplinary Conference on Web Accessibililty* (W4A) (pp. 1-6). ACM.

[9] Archer, N.N., Fevrier-Thomas, U.U., Lokker, C.C., McKibbon, K.A.K. and Straus, S.E.S. (2011). Personal health records: a scoping review. In: *Journal of the American Medical Informatics Association*. 18(4), 515–522.

[10] American Medical Informatics Association. (2007). Value of Personal Health Records: A Joint Position Statement for Consumers of Health Care. In: Journal of AHIMA, 78(4), 22-24.

[11] Baharin, H. (2009). Mutuality: A Key Gap in the Move to Telecare. In: *Proceedings of the 10th International Conference NZ Chapter of the ACM's Special Interest Group on Human-Computer Interaction* (pp. 5-12). ACM.

[12] Baird, A., North, F. and Raghu, T.S. (2011). Personal Health Records (PHR) and the future of the physician-patient relationship. In: *Proceedings of the 2011 iConference* (pp. 281-288). ACM.

[13] Bamis, A., Lymberopoulos, D., Teixeira, T. and Savvides, A. (2010). The BehaviorScope framework for enabling ambient assisted living. In: *Personal and Ubiquitous Computing*. 14(6), 473–487.

[14] Bashshur, R.L., Reardon, T.G. and Shannon, G.W. (2000). Telemedicine: a new health care delivery system. In: *Annual review of public health*. 21(1), 613–637.

[15] Belden, J.L., Grayson, R. and Barnes, J. (2009). Defining and testing EMR usability: Principles and proposed methods of EMR usability evaluation and rating. In: *Healthcare Information and Management Systems Society (HIMSS).*

[16] Benedek, J. and Miner, T. (2002). Measuring Desirability: New methods for evaluating desirability in a usability lab setting. In: *Proceedings of UPA 2002 Conference*.

[17] Botsis, T. and Hartvigsen, G. (2008). Current status and future perspectives in telecare for elderly people suffering from chronic diseases. In: *Journal of Telemedicine and Telecare*. 14(4), 195–203.

[18] Bourgeois, F.C., Mandl, K.D. and Shaw, D. (2009). Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population. In: *AMIA annual symposium proceedings* Vol. 2009, p. 65. *American Medical Informatics Association.*

[19] Brennan, P.F., Downs, S. and Casper, G. (2010). Project HealthDesign: rethinking the power and potential of personal health records. In: *Journal of biomedical informatics*. 43(5), S3–S5.

[20] Burdick, D.C. and Kwon, S. (2004). Gerotechnology: Research and Practice in Technology and Aging. In: *Springer Publishing Company.*

[21] Calvo, R.A. and Peters, D. (2014). In: *Positive Computing*. MIT Press.

[22] Carneiro, C.M.D.S. (2012). Voluntary Electronic Patient Record State Of The Art. In: *Faculdade de Ciências da Saúde da Universidade da Beira Interior.*

[23] Chewning, B., Bylund, C.L., Shah, B., Arora, N.K., Gueguen, J.A. and Makoul, G. (2012). Patient preferences for shared decisions: a systematic review. In: *Patient education and counseling*. 86(1), 9–18.

[24] Chisnell, D.E., Redish, J.C.G. and Lee, A. (2006). New heuristics for understanding older adults as web users. In: *Technical Communication*. 53(1), 39–59.

[25] Chun, Y.J. and Patterson, P.E. (2012). A usability gap between older adults and younger adults on interface design of an Internet-based telemedicine system. In: *Work*. 41(Supplement 1), 349–352.

[26] Chung, C. F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J. A., & Munson, S. A. (2016). Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In: *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (pp. 770-786). ACM.

[27] Claypoole, V. L., Schroeder, B. L., & Mishler, A. D. (2016). Keeping in Touch: Tactile Interface Design for Older Users. In: *ergonomics in design,* 24(1), 18-24.

[28] Cohen, D.J., Keller, S.R., Hayes, G.R., Dorr, D.A., Ash, J.S. and Sittig, D.F. (2014).

Developing a model for understanding patient collection of observations of daily living: a qualitative meta-synthesis of the Project HealthDesign program. In: *Personal and Ubiquitous Computing*. 19(1), 91–102.

[29] Chen, Y., Tang, C., Cheng, K., & Park, S. Y. (2012). Bridging clinical and non-clinical health practices: opportunities and challenges. In: *CHI'12 Extended Abstracts on Human Factors in Computing Systems* (pp. 2723-2726). ACM.

[30] Collaborative Usability Inspection: http://www.foruse.com/presentations/inspections.pdf. Accessed: 2014-04-24.

[31] Cooper, A., Reimann, R. and Cronin, D. (2012). In: *About Face 3*. Wiley.

[32] Costello, K. and Wildemuth, B. (2012). Who should have access to my personal health record? In: *University of North Carolina at Chapel Hill, NC.*

[33] Cota, M.P., Thomaschewski, J., Schrepp, M. and Gonçalves, R. (2014). Efficient Measurement of the User Experience. A Portuguese Version. In: *Procedia Computer Science*. 27, 491–498.

[34] Cronin, C. (2006). Personal Health Records: An overview of what is available to the public. In: *AARP Public Policy Institute*, 1–23.

[35] Daniel, K., Cason, C.L. and Ferrell, S. (2009). Assistive technologies for use in the home to prolong independence. In: *Proceedings of the 2nd International Conference on PErvasive Technologies Related to Assistive Environments*.

[36] Davis, D.L. (2008). *Acceptance of personal health record technology: A survey analysis of the elderly*. In: ProQuest Dissertations and Theses.

[37] Davis, R.E.R., Jacklin, R.R., Sevdalis, N.N. and Vincent, C.A.C. (2007). Patient involvement in patient safety: what factors influence patient participation and engagement? In: *Health Expectations*. 10(3), 259–267.

[38] Delbanco, T., Walker, J., Bell, S.K., Darer, J.D., Elmore, J.G., Farag, N., Feldman, H.J., Mejilla, R., Ngo, L., Ralston, J.D., Ross, S.E., Trivedi, N., Vodicka, E. and Leveille, S.G. (2012). Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead. In: *Annals of Internal Medicine*. 157(1), 461–470.

[39] Deloitte (2011). *Saúde em análise*. Deloitte.

[40] Demiris, G., Thompson, H., Boquet, J., Le, T., Chaudhuri, S. and Chung, J. (2013). Older adults' acceptance of a community-based telehealth wellness system. In: *Informatics for Health and Social Care*. 38(1), 27–36.

[41] Demiris, G., Thompson, H.J., Reeder, B., Wilamowska, K. and Zaslavsky, O. (2013). Using informatics to capture older adults' wellness. In: *International Journal of Medical Informatics*. 82(11), e232–e241.

[42] Denmark Leads the Way in Digital Care - The New York Times: http://www.nytimes.com/2010/01/12/health/12denmark.html?mcubz=1. Accessed: 2017-08-20.

[43] Detmer, D.E., Bloomrosen, M., Raymond, B. and Tang, P. (2008). Integrated personal health records: Transformative tools for consumer-centric care. *BMC* In:

Medical Informatics and Decision Making. 8(1), 45.

[44] Dexter, P.R., Miller, D.K., Clark, D.O., Weiner, M., Harris, L.E., Livin, L., Myers, I., Shaw, D., Blue, L.A., Kunzer, J. and Overhage, J.M. (2010). Preparing for an aging population and improving chronic disease management. In: *AMIA Annual Symposium Proceedings. American Medical Informatics Association,* p. 162.

[45] Diener, E., Emmons, R.A., Larsen, R.J. and Griffin, S. (1985). The Satisfaction With Life Scale. In: *Journal of Personality Assessment*. 49(1), 71–75.

[46] Doyle, J., O'Mullane, B., McGee, S. and Knapp, R.B. (2012). YourWellness: designing an application to support positive emotional wellbeing in older adults. In In: *Proceedings of the 26th Annual BCS Interaction Specialist Group Conference on People and Computers* (pp. 221-226). British Computer Society.

[47] Doyle, J., Walsh, L., Sassu, A. and McDonagh, T. (2014). Designing a wellness self-management tool for older adults: results from a field trial of YourWellness. In: *Proceedings of the 8th international conference on pervasive computing technologies for healthcare* (pp. 134-141). ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering).

[48] eHGI Article 14 eHealth Network - Conclusions and Discussion Papers - All Documents: http://www.ehgi.eu/Pages/default.aspx?articleID=22 Accessed: 2012-11-24

[49] Emont, S. (2011). Measuring the Impact of Patient Portals: What the Literature Tells Us. 2011. In: *California Healthcare Foundation,* 1-20.

[50] Endsley, S., Kibbe, D.C., Linares, A. and Colorafi, K. An Introduction to Personal Health Records. (2006). In: *Family practice management,* 13(5), 57.

[51] epsos 2012. Final definition of functional service requirements: patient summary: http://www.epsos.eu/uploads/tx_epsosfileshare/D3.2.2_Final_Definition_Functional_Service_Req_Patient_Summary.pdf Accessed: 2013-09-24.

[52] epsos, Open eHealth initiative for a European large scale pilot of patient summary and electronic prescription eHealth, Recommendations D2.2.7, Policy and Strategy: http://www.epsos.eu/uploads/tx_epsosfileshare/D2.2.7_Recommendations_v1.5.pdf Accessed: 2013-10-29.

[53] epsos.eu: http://epsos.eu. Accessed: 2014-12-10.

[54] Figueiredo, J.P., Costa, C.J. and Aparicio, M. (2012). Patient Health Portal: a calendar paradigm. In: *Proceedings of the Workshop on Open Source and Design of Communication* (pp. 39-44). ACM.

[55] Fitzpatrick, G. and Ellingsen, G. (2012). A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. In: *Computer Supported Cooperative Work (CSCW)*. 22(4-6), 609–665.

[56] Fling, B. (2009). *Mobile Design and Development*. In: O'Reilly Media, Inc.

[57] Fonda, S.J., Kedziora, R.J., Vigersky, R.A. and Bursell, S.-E. (2010). Evolution of a web-based, prototype Personal Health Application for diabetes self-management. In: *Journal of biomedical informatics*. 43(5), S17–S21.

[58] Fontes, A., Botelho, A. and Fernandes, A. (2014). A Biopsychosocial Evaluation Method and the International Classification of Functioning, Disability, and Health (ICF). In: *Educational Gerontology*. 40(9), 686–699.

[59] Feliciani, F. (2004). Medical care from space: Telemedicine. In: *Studies in health technology and informatics*, 104, 207-212.

[60] Fuchsberger, M.V. (2008). Ambient Assisted Living: Elderly People's Needs and How to Face Them. In: *Proceedings of the 1st ACM international workshop on Semantic ambient media experiences* (pp. 21-24). ACM.

[61] Garrett, J.J. (2003). *The Elements of User Experience*. Peachpit Press.

[62] Grant, R.W., Wald, J.S., Poon, E.G., Schnipper, J.L., Gandhi, T.K., Volk, L.A. and Middleton, B. (2006). Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: patient gateway for diabetes collaborative care. In: *Diabetes Technology &amp Therapeutics*. 8(5), 576–586.

[63] Grönvall, E. and Kyng, M. (2012). On participatory design of home-based healthcare. In: *Cognition, Technology & Work*. 15(4), 389–401.

[64] Haggstrom, D.A., Saleem, J.J., Russ, A.L., Jones, J., Russell, S.A. and Chumbler, N.R. (2011). Lessons learned from usability testing of the VA's personal health record. In: *Journal of the American Medical Informatics Association*. 18(Supplement 1), i13–i17.

[65] Halamka, J.D., Mandl, K.D. and Tang, P.C. (2007). Early Experiences with Personal Health Records. In: *Journal of the American Medical Informatics Association*. 15(1), 1–7.

[66] Hardstone, G., Hartswood, M., Procter, R., Slack, R., Voss, A. and Rees, G. (2004). Supporting informality: team working and integrated care records. In: *Proceedings of the 2004 ACM conference on Computer supported cooperative work*. (pp. 142–151).

[67] Healthcare Experience Design Conference - Boston 2013: http://healthcareexperiencedesign.com/speakers/speakers-bio-heywood.php Accessed: 2013-05-27.

[68] Healthcare information technology report, published by 2020health.org: Personal Health Records - Putting patients in control? http://www.2020health.org/2020health/Publications/publications-2012/Public-Health-Records.html Accessed: 2013-05-30.

[69] Heart, T. and Kalderon, E. (2013). Older adults: Are they ready to adopt health-related ICT? In: *International Journal of Medical Informatics*. 82(11), e209–e231.

[70] Hilligoss, P.B. and Cohen, M.D. (2009). Handoffs in Hospitals: A review of the literature on information exchange while transferring patient responsibility or control. In: *School of Information University of Michigan*.

[71] Huba, N. and Zhang, Y. (2012). Designing Patient-Centered Personal Health Records (PHRs): Health Care Professionals' Perspective on Patient-Generated Data. In: *Journal of Medical Systems*. 36(6), 3893–3905.

[72] Huh, J., Le, T., Reeder, B., Thompson, H.J. and Demiris, G. (2013). Perspectives

on wellness self-monitoring tools for older adults. *International Journal of Medical Informatics*. 82(11), 1092–1103.

[73] Hulse, N.C., Ranade-Kharkar, P., Post, H., Wood, G.M., Williams, M.S. and Haug, P.J. (2011). Development and early usage patterns of a consumer-facing family health history tool. In: *In AMIA Annual Symposium Proceedings* (Vol.2011, p.578).

[74] In Denmark's Electronic Health Records Program, a Lesson for the U.S.: http://content.time.com/time/health/article/0,8599,1891209,00.html Accessed: 2014-04-24.

[75] Irizarry, T., Dabbs, A.D. and Curran, C.R. (2015). Patient Portals and Patient Engagement: A State of the Science Review. In: *Journal of Medical Internet Research*. 17(6), e148–e148.

[76] Johnston, D., Kaelber, D.C., Pan, E.C., Bu, D., Shah, S., Hook, J.M. and Middleton, B. (2007). A Framework and Approach for Assessing the Value of Personal Health Records (PHRs). In: *AMIA Annual Symposium Proceedings*. p. 374. American Medical Informatics Association.

[77] Kharrazi, H., Chisholm, R., VanNasdale, D., & Thompson, B. (2012). Mobile personal health records: an evaluation of features and functionality. In: *International journal of medical informatics*, 81(9), 579-593.

[78] Kaelber, D. and Pan, E.C. (2008). The value of personal health record (PHR) systems. In: *AMIA Annual Symposium Proceedings* (Vol. 2008, p. 343). American Medical Informatics Association.

[79] Kaelber, D.C.D., Jha, A.K.A., Johnston, D.D., Middleton, B.B. and Bates, D.W.D. (2008). A research agenda for personal health records (PHRs). In: *Journal of the American Medical Informatics Association*. 15(6), 729–736.

[80] Kahneman, D., Diener, E. and Schwarz, N. (1999). Well-Being: Foundations of Hedonic Psychology. *Russell Sage Foundation.*

[81] Katz, S.J. and Moyer, C.A. (2004). The emerging role of online communication between patients and their providers. In: *Journal of General Internal Medicine*. 19(9), 978–983.

[82] Kaufman, D.R., Patel, V.L., Hilliman, C., Morin, P.C., Pevzner, J., Weinstock, R.S., Goland, R., Shea, S. and Starren, J. (2003). Usability in the real world: assessing medical information technologies in patients' homes. In: *Journal of biomedical informatics*. 36(1), 45–60.

[83] Kensing, F. (2012). Personal health records. In: *Studies in Health Technology and Informatics*. pp. 9–13.

[84] Keselman, A. and Smith, C.A. (2012). A classification of errors in lay comprehension of medical documents. In: *Journal of biomedical informatics*. 45(6), 1151–1163.

[85] Ketabdar, H. and Lyra, M. (2010). ActivityMonitor: assisted life using mobile phones. In: *Proceedings of the 15th international conference on Intelligent user interfaces* (pp. 417-418). ACM.

[86] Kharrazi, H., Chisholm, R., VanNasdale, D. and Thompson, B. (2012). Mobile

personal health records: An evaluation of features and functionality. In: *International Journal of Medical Informatics*. 81(9), 579–593.

[87] Khosravi, P., & Ghapanchi, A. H. (2016). Investigating the effectiveness of technologies applied to assist seniors: A systematic literature review. In: *International journal of medical informatics,* 85(1), 17-26.

[88] Kientz, J. A., Choe, E. K., Birch, B., Maharaj, R., Fonville, A., Glasson, C., & Mundt, J. (2010). Heuristic evaluation of persuasive health technologies. In: *Proceedings of the 1st ACM International Health Informatics Symposium* (pp. 555-564). ACM.

[89] Kim, E.-H., Stolyar, A., Lober, W.B., Herbaugh, A.L., Shinstrom, S.E., Zierler, B.K., Soh, C.B. and Kim, Y. (2009). Challenges to using an electronic personal health record by a low-income elderly population. In: *Journal of Medical Internet Research*. 11(4), e44–e44.

[90] Kim, M.I. and Johnson, K.B. (2004). Patient Entry of Information: Evaluation of User Interfaces. In: *Journal of Medical Internet Research*. 6(2), e13.

[91] Kim, M.I. and Johnson, K.B. (2002). Personal health records: evaluation of functionality and utility. In: *Journal of the American Medical Informatics Association*. 9(2), 171–180.

[92] Kjeldskov, J. and Skov, M.B. (2006). Exploring context-awareness for ubiquitous computing in the healthcare domain. In: *Personal and Ubiquitous Computing*. 11(7), 549–562.

[93] Kleinpell, R.M. and Avitall, B. (2007). Integrating telehealth as a strategy for patient management after discharge for cardiac surgery: results of a pilot study. In: *Journal of Cardiovascular Nursing*. 22(1), 38–42.

[94] Koch, S. (2006). Home telehealth—Current state and future trends. In: *International Journal of Medical Informatics*. 75(8), 565–576.

[95] Krist, A.H., Peele, E., Woolf, S.H., Rothemich, S.F., Loomis, J.F., Longo, D.R. and Kuzel, A.J. (2011). Designing a patient-centered personal health record to promote preventive care. In: *BMC Medical Informatics and Decision Making*. 11(1), 73.

[96] Keselman, A., & Smith, C. A. (2012). A classification of errors in lay comprehension of medical documents. In: *Journal of biomedical informatics*, 45(6), 1151-1163.

[97] Le, T., Wilamowska, K., Demiris, G. and Thompson, H. (2012). Integrated data visualisation: an approach to capture older adults' wellness. In: *International Journal of Electronic Healthcare*. 7(2), 89.

[98] Leveille, S.G., Walker, J., Ralston, J.D., Ross, S.E., Elmore, J.G. and Delbanco, T. (2012). Evaluating the impact of patients" online access to doctors" visit notes: designing and executing the OpenNotes project. In: *BMC Medical Informatics and Decision Making*. 12(1), 32–32.

[99] Le, T., Reeder, B., Yoo, D., Aziz, R., Thompson, H. J., & Demiris, G. (2015). An evaluation of wellness assessment visualizations for older adults. In: *Telemedicine and e-Health*, 21(1), 9-15.

[100] Li, I. (2010). A Stage-Based Model of Personal Informatics Systems. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 557-566). ACM.

[101] Li, Y.C., Detmer, D.E., Shabbir, S.A., Nguyen, P.A., Jian, W.S., Mihalas, G.I., Shortliffe, E.H., Tang, P., Haux, R. and Kimura, M. (2011). A global travelers' electronic health record template standard for personal health records. In: *Journal of the American Medical Informatics Association*. 19(1), 134–136.

[102] Life Cycle - The new app that tracks your time and life automatically: http://www.northcube.com/lifecycle/press/introducing-life-cycle-new-app-tracks-time-life-automatically/. Accessed: 2017-07-30.

[103] Lindlof, T.R. and Taylor, B.C. (2010). In: *Qualitative Communication Research Methods*. Sage Publications, Incorporated.

[104] Liu, L.S., Shih, P.C. and Hayes, G.R. (2011). Barriers to the adoption and use of personal health record systems. In: *Proceedings of the 2011 iConference* (pp. 363-370). ACM.

[105] Lober, W.B., Zierler, B., Herbaugh, A., Shinstrom, S.E., Stolyar, A., Kim, E.H. and Kim, Y. (2006). Barriers to the use of a personal health record by an elderly population. In: *AMIA Annual Symposium Proceedings* (Vol. 2006, p. 514). American Medical Informatics Association.

[106] Ludwig, W., Wolf, K.-H., Duwenkamp, C., Gusew, N., Hellrung, N., Marschollek, M., Wagner, M. and Haux, R. (2012). Health-enabling technologies for the elderly – An overview of services based on a literature review. In: *Computer Methods and Programs in Biomedicine*. 106(2), 70–78.

[107] Luo, G., Tang, C. and Thomas, S.B. (2012). Intelligent personal health record: experience and open issues. In: *Journal of Medical Systems*. 36(4), 2111–2128.

[108] Lutze, R. and Waldhör, K. (2015). A Smartwatch Software Architecture for Health Hazard Handling for Elderly People. In: *Healthcare Informatics (ICHI), 2015 International Conference on (pp. 356-361). IEEE.*

[109] Making Your Website Senior Friendly: https://www.nlm.nih.gov/pubs/checklist.pdf Accessed: 2012-10-26.

[110] McNeill, A. R., Coventry, L., Pywell, J., & Briggs, P. (2017). Privacy Considerations when Designing Social Network Systems to Support Successful Ageing. In: *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 6425-6437). ACM.

[111] Manasa, D., & Khanna, K. R. (2015). Sharing of PHR's in Cloud Computing. In: *International Journal of Computer Science and Network Security (IJCSNS),* 15(11), 86.

[112] Mandl, K.D., Mandel, J.C., Murphy, S.N., Bernstam, E.V., Ramoni, R.L., Kreda, D.A., McCoy, J.M., Ben Adida and Kohane, I.S. (2012). The SMART Platform: early experience enabling substitutable applications for electronic health records. In: *Journal of the American Medical Informatics Association,* 19(4), 597-603.

[113] Mandl, K.D.K., Simons, W.W.W., Crawford, W.C.R.W. and Abbett, J.M.J. (2007). Indivo: a personally controlled health record for health information exchange and communication. In: *BMC Medical Informatics and Decision Making*. 7(1), 25–25.

[114] Marchionini, G., Rimer, B. K., & Wildemuth, B. (2007). Evidence base for personal health record usability: Final report to the National Cancer Institute. In: *University of North Carolina at Chapel Hill, School of Information and Library Science.*

[115] Marcu, G., Dey, A. K., Kiesler, S., & Reddy, M. (2016). Time to reflect: Supporting health services over time by focusing on collaborative reflection. In: *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (pp. 954-964). ACM.

[116] Markle Foundation 2004 Final Report, Connecting Americans to their healthcare: https://www.markle.org/sites/default/files/CnctAmerHC_fullreport.pdf Accessed: 2012-10-20.

[117] McElligott, J.T. and Darden, P.M. (2010). Are Patient-Held Vaccination Records Associated With Improved Vaccination Coverage Rates? In: *Pediatrics*. 125(3), e467–e472.

[118] McLaughlin, A.C., Rogers, W.A. and Fisk, A.D. (2009). Using direct and indirect input devices. In: *ACM Transactions on Computer-Human Interaction*. 16(1), 1–15.

[119] Meadows, G. and Chaiken, B.P. (2003). Using IT to improve clinical teamwork and communication. In: *Nursing Economics*. 21(1), 33–34.

[120] Member Companies | Dossia Personal Health Platform: http://dossia.org/ Accessed: 2012-12-04.

[121] Microsoft HealthVault: https://international.healthvault.com/pt/en Accessed: 2012-11-19.

[122] MobiHealth 2, 2.A.N. (2011). *Wireless mobile communication and healthcare.*

[123] Mota-Pinto, A., Rodrigues, V., Botelho, A., Veríssimo, M.T., Morais, A., Alves, C., Rosa, M.S. and de Oliveira, C.R. (2011). A socio-demographic study of aging in the Portuguese population: the EPEPP study. In: *Archives of Gerontology and Geriatrics*. 52(3), 304–308.

[124] Murphy, A.R., Reddy, M.C. and McNeese, N.J. (2014). Exploring the perceptions and use of electronic medical record systems by non-clinicians. In: *Proceedings of the 2014 conference on Designing interactive systems* (pp. 429-432). ACM.

[125] Nagykaldi, Z., Aspy, C.B., Chou, A. and Mold, J.W. (2012). Impact of a Wellness Portal on the Delivery of Patient-Centered Preventive Care. In: *The Journal of the American Board of Family Medicine*. 25(2), 158–167.

[126] Nave, C., Correia, N. and Romão, T. (2016). Exploring Emotions through Painting, Photography and Expressive Writing. In: *Proceedings of the 13th International Conference on Advances in Computer Entertainment Technology* (p. 19). ACM.

[127] Nazi, K.M. (2010). Veterans" voices: use of the American Customer Satisfaction Index (ACSI) Survey to identify My HealtheVet personal health record users" characteristics, needs, and preferences. In: *Journal of the American Medical Informatics Association*. 17(2), 203–211.

[128] Neuhauser, L., Kreps, G.L., Morrison, K., Athanasoulis, M., Kirienko, N. and Van Brunt, D. (2013). Using design science and artificial intelligence to improve health communication: ChronologyMD case example. In: *Patient education and counseling*.

92(2), 211–217.

[129] Neuhauser, L., Rothschild, B., Graham, C., Ivey, S.L. and Konishi, S. (2009). Participatory Design of Mass Health Communication in Three Languages for Seniors and People With Disabilities on Medicaid. In: *American Journal of Public Health*. 99(12), 2188–2195.

[130] Norman, D.A. (2010). *Living with Complexity*. MIT Press.

[131] Older Users Online: WAI Guidelines Address Older Users Web Experience: http://www.w3.org/WAI/posts/2009/older-users-online Accessed: 2012-10-26.

[132] Oppenauer, C., Preschl, B., Kalteis, K. and Kryspin-Exner, I. (2007). Technology in old age from a psychological point of view. In: *HCI and Usability for Medicine and Health Care*. pp. 133–142.

[133] Osborn, C.Y., Rosenbloom, S.T., Stenner, S.P., Anders, S., Muse, S., Johnson, K.B., Jirjis, J. and Jackson, G.P. (2011). MyHealthAtVanderbilt: policies and procedures governing patient portal functionality. In: *Journal of the American Medical Informatics Association*. 18(Supplement 1), i18–i23.

[134] Pagliari, C., Detmer, D. and Singleton, P. (2007) In: *Electronic personal health records: emergence and implications for the UK*. London: Nuffield Trust.

[135] Pagliari, C., Detmer, D. and Singleton, P. (2007). Potential of electronic personal health records. *BMJ: British Medical Journal,* 335(7615), 330.

[136] Patel, V.N., Abramson, E., Edwards, A.M., Cheung, M.A., Dhopeshwarkar, R.V. and Kaushal, R. (2011). Consumer attitudes toward personal health records in a beacon community. In: *The American journal of managed care*. 17(4), e104–e120.

[137] Patel, V.N., Dhopeshwarkar, R.V., Edwards, A., Barrón, Y., Sparenborg, J. and Kaushal, R. (2010). Consumer Support for Health Information Exchange and Personal Health Records: A Regional Health Information Organization Survey. In: *Journal of Medical Systems*. 36(3), 1043–1052.

[138] Puustjärvi, J., & Puustjärvi, L. (2012). Ontology-based integration of clinical documents. In: *Proceedings of the 14th International Conference on Information Integration and Web-based Applications & Services* (pp. 342-347). ACM.

[139] Pearce, C. and Bainbridge, M. (2014). A personally controlled electronic health record for Australia. In: *Journal of the American Medical Informatics Association*. 21(4), 707–713.

[140] Pedell, S., Vetere, F., Kulik, L., Ozanne, E. and Gruner, A. (2010). Social isolation of older people: the role of domestic technologies. In: *OZCHI '10: Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction*. (2010).

[141] Peregrin, T. (2009). Personal and Electronic Health Records: Sharing Nutrition Information across the Health Care Community. In: *Journal of the American Dietetic Association*. 109(12), 1988–1991.

[142] Personal Health Records and Personal Health Record Systems, A Report Recommendation from the National Committee on Vital and Health Services. U.S Department of Health and Human Services: http://ncvhs.us/wp-

content/uploads/2014/05/0602nhiirpt.pdf Accessed: 2014-08-20.

[143] Phan, D., Siong, L.Y., Pathirana, P.N. and Seneviratne, A. (2015). Smartwatch: Performance evaluation for long-term heart rate monitoring. In: *Bioelectronics and Bioinformatics (ISBB), 2015 International Symposium* (pp. 144-147). IEEE.

[144] Pinto, J.M., Coppola, J.F., Stanford, M., Gaur, C. and Gaur, D. (2014). Educational effects of telehealth implementation on older adults with socio-economic disparities. In: *Systems, Applications and Technology Conference (LISAT), 2014 IEEE Long Island* (pp. 1-6). IEEE.

[145] Poon, E.G., Wald, J.S., Bates, D.W., Middleton, B., Kuperman, G.J. and Gandhi, T.K. (2003). Supporting Patient Care Beyond the Clinical Encounter - Three Informatics Innovations from Partners Health Care. In: *AMIA Annual Symposium Proceedings* (Vol. 2003, p. 1070). American Medical Informatics Association.

[146] Porter, J. (2008). *Designing for the Social Web*. New Riders.

[147] Personal Health Record Practice AHIMA Council. (2006). Helping consumers select PHRs: questions and considerations for navigating an emerging market. Helping Consumers Select PHRs: Questions and Considerations for Navigating an Emerging Market/AHIMA. In: *American Health Information Management Association.*

[148] Price, M.M., Pak, R., Müller, H. and Stronge, A. (2012). Older adults' perceptions of usefulness of personal health records. In: *Universal Access in the Information Society*. 12(2), 191-204.

[149] Pries-Heje, J., Venable, J. J., Bunker, D., Russo, N. L., & DeGross, J. I. (2014). Human Benefit through the Diffusion of Information Systems Design Science Research: IFIP WG 8.2/8.6 International Working Conference, Perth, Australia. *Springer Publishing Company, Incorporated.*

[150] Park, K., Becker, E., Vinjumur, J. K., Le, Z., & Makedon, F. (2009). Human behavioral detection and data cleaning in assisted living environment using wireless sensor networks. In *Proceedings of the 2nd International Conference on PErvasive Technologies Related to Assistive Environments* (p. 7). ACM.

[151] Program ESP (Evidence-based Synthesis Program), Center West Los Angeles VA Medical Center. 2012. Secure Messaging between Providers and Patients, and Patients' Access to Their Own Medical Record: https://www.hsrd.research.va.gov/publications/esp/myhealthevet.pdf Accessed: 2013-03-16.

[152] Project HealthDesign: https://www.rwjf.org/en/library/research/2010/10/project-healthdesign-.html Accessed: 2013-01-13.

[153] PROMIS (Patient-Reported Outcomes Measurement Information System): http://www.healthmeasures.net/explore-measurement-systems/promis Accessed: 2013-01-13.

[154] Quist, J. and Vergragt, P. (2006). Past and future of backcasting: The shift to stakeholder participation and a proposal for a methodological framework. In: *Futures*. 38(9), 1027–1045.

[155] Reisberg, D. (2010). *Cognition: Exploring the Science of the Mind*. W W Norton & Co Inc.

[156] Reti, S.R., Feldman, H.J., Ross, S.E. and Safran, C. (2010). Improving personal health records for patient-centered care. In: *Journal of the American Medical Informatics Association*. 17(2), 192–195.

[157] Rodolfo, I., Correia, N., Sousa, M., Sá, P. and Duarte, C. (2016). How Far in the Future Will We Start From? In: *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems* (pp. 899-909). ACM.

[158] Rodrigues, V., Mota-Pinto, A., de Sousa, B., Botelho, A., Alves, C. and de Oliveira, C.R. 2014. The aging profile of the Portuguese population: a principal component analysis. In: *Journal of community health*. 39(4), 747–752.

[159] Rodríguez, M. D., García-Vázquez, J. P., & Andrade, Á. G. May. Design dimensions of ambient information systems to facilitate the development of AAL environments. In: *Proceedings of the 4th International Conference on PErvasive Technologies Related to Assistive Environments* (p. 4). ACM.

[160] Romero, J., López, P., Noguera, J.L.V., Cappo, C., Pinto-Roa, D.P. and Villalba, C. 2016. Integrated, reliable and cloud-based personal health record: A scoping review. *arXiv preprint arXiv:1609.03615*.

[161] Round Two: A Dossia Update: http://chilmarkresearch.com/2009/10/26/round-two-a-dossia-update/ Accessed: 2012-12-04.

[162] Ruggiero, C., Sacile, R. and Giacomini, M. (1999). Home telecare. In: *Journal of Telemedicine and Telecare*. 5(1), 11–17.

[163] Sandstrom, G.M., Lathia, N., Mascolo, C. and Rentfrow, P.J. (2016). Opportunities for smartphones in clinical care: the future of mobile mood monitoring. In: *The Journal of clinical psychiatry*. 77(2), e135–7.

[164] Saparova, D. (2012). Motivating, influencing, and persuading patients through personal health records: a scoping review. In: *Perspectives in health information management / AHIMA, American Health Information Management Association*. 9(1), 1f–1f.

[165] Say, R., Murtagh, M. and Thomson, R. (2006). Patients' preference for involvement in medical decision making: a narrative review. In: *Patient education and counseling*. 60, 2(1), 102–114.

[166] Simpósio de Medicina Geriátrica: Active Aging – International Conference 2012: The Future of Aging. https://issuu.com/aagi-id/docs/ebook_-the_future_of_aging__scientific_posters___c Accessed at: 2012-06-12

[167] Seale, J., McCreadie, C., Turner-Smith, A. and Tinker, A. 2002. Older people as partners in assistive technology research: the use of focus groups in the design process. In: *Technology and Disability*. 14(1), 21–29.

[168] Seamlessness in the Omnichannel User Experience: https://www.nngroup.com/articles/seamless-cross-channel/ Accessed at: 2017-07-31.

[169] Severity Ratings for Usability Problems: https://www.nngroup.com/articles/how-

to-rate-the-severity-of-usability-problems/ Accessed: 2017-07-09.

[170] Shah, M.N., Gillespie, S.M., Wood, N., Wasserman, E.B., Nelson, D.L., Dozier, A. and McConnochie, K.M. (2013). High-Intensity Telemedicine-Enhanced Acute Care for Older Adults: An Innovative Healthcare Delivery Model. In: *Journal of the American Geriatrics Society*. 61(11), 2000–2007.

[171] Shah, S., Shah, S.S., Kaelber, D.C., Kaelber, D.C., Vincent, A., Pan, E.C., Pan, E., Johnston, D. and Middleton, B. (2008). A cost model for personal health records (PHRs). In: *AMIA Annual Symposium Proceedings (Vol. 2008, p. 657).* American Medical Informatics Association.

[172] Shank, N. 2012. In: *Behavioral Health Providers and Electronic Health Records*. Proquest, Umi Dissertation Publishing.

[173] Sox, C. M., Gribbons, W. M., Loring, B. A., Mandl, K. D., Batista, R., & Porter, S. C. (2010). Patient-centered design of an information management module for a personally controlled health record. In: *Journal of medical Internet research*, 12(3).

[174] Siek, K.A., Khan, D.U., Ross, S.E., Haverhals, L.M., Meyers, J. and Cali, S.R. (2011). Designing a personal health application for older adults to manage medications: a comprehensive case study. In: *Journal of Medical Systems*. 35(5), 1099–1121.

[175] Silsand, L. and Ellingsen, G. (2016). Complex Decision-Making in Clinical Practice. In: *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (pp. 993-1004). ACM.

[176] Sleep Cycle alarm clock: *https://www.sleepcycle.com/* Accessed: 2017-07-30.

[177] Smart Open Services for European Patients Open eHealth initiative for a European large scale pilot of patient summary and electronic prescription: *http://www.epsos.eu/uploads/tx_epsosfileshare/D2.2.7_Recommendations_v1.5.pdf* Accessed: 2014-12-10.

[178] Sparkline theory and practice: *http://www.edwardtufte.com/bboard/q-and-a-fetch-msg?msg_id=0001OR*. Accessed: 2014-04-24.

[179] Spencer, D. 2011. *Card Sorting*. O'Reilly Media, Inc.

[180] Spradley, J.P. 1979. *The ethnographic interview*. Wadsworth Pub Co.

[181] Siek, K. A., Ross, S. E., Khan, D. U., Haverhals, L. M., Cali, S. R., & Meyers, J. 2010. Colorado Care Tablet: the design of an interoperable Personal Health Application to help older adults with multimorbidity manage their medications. In: *Journal of biomedical informatics,* 43(5), S22-S26.

[182] Staroselsky, M., Volk, L.A., Tsurikova, R., Pizziferri, L., Lippincott, M., Wald, J. and Bates, D.W. 2006. Improving electronic health record (EHR) accuracy and increasing compliance with health maintenance clinical guidelines through patient access and input. In: *International Journal of Medical Informatics*. 75(10), 693–700.

[183] Steele, R. and Lo, A. (2012). Telehealth and ubiquitous computing for bandwidth-constrained rural and remote areas. In: *Personal and Ubiquitous Computing*. 17(3), 533–543.

[184] Stuck, A.E. and Iliffe, S. (2011). Comprehensive geriatric assessment for older adults. In: *BMJ*. d6799–d6799.

[185] Study identifies patients most willing to use personal health records - amednews.com: http://www.activdoctorsonline.com/news/american-medical-news-study-identifies-patients-personal-health-records/ Accessed: 2012-11-19.

[186] sundhed.dk - den offentlige sundhedsportal: https://www.sundhed.dk/ Accessed: 2017-08-21.

[187] Sunyaev, A., Chornyi, D., Mauro, C., & Krcmar, H. (2010). Evaluation framework for personal health records: Microsoft HealthVault vs. Google Health. In: *System Sciences (HICSS), 2010 43rd Hawaii International Conference* (pp. 1-10). IEEE.

[188] Symon, G., Long, K. and Ellis, J. (1996). The Coordination of Work Activities - Cooperation and Conflict in a Hospital Context. In: *Computer Supported Cooperative Work*. (1996).

[189] Tang, P.C.P., Ash, J.S.J., Bates, D.W.D., Overhage, J.M.J. and Sands, D.Z.D. (2006). Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. In: *Journal of the American Medical Informatics Association*. 13(2), 121–126.

[190] Thinking about Stage 3 of Meaningful Use « Patients Know Best blog: http://blog.patientsknowbest.com/2012/11/12/thinking-about-stage-3-of-meaningful-use/ Accessed: 2012-11-19.

[191] Thomas, D.R. (2003). *A general inductive approach for qualitative data analysis: School of Population Health*. In: University of Auckland.

[192] Thompson, H.J., Demiris, G., Rue, T., Shatil, E., Wilamowska, K., Zaslavsky, O. and Reeder, B. (2011). A Holistic Approach to Assess Older Adults' Wellness Using e-Health Technologies. In: *Telemedicine and e-Health*. 17(10), 794–800.

[193] Trimpop, J., Haescher, M. and Bieber, G. (2015). The Digital Health Companion: Personalized Health Support on Smartwatches via Recognition of Activity-and Vital-Data. In: *Proceedings of the International Summer School on Visual Computing 2015*. Fraunhofer-Institut für Graphische Datenverarbeitung.

[194] Trotter, F. and Uhlman, D. (2011). *Meaningful Use and Beyond: A Guide for IT Staff in Health Care*. O'Reilly Media.

[195] Unger, R. and Chandler, C. (2012). *A Project Guide to UX Design: For user experience designers in the field or in the making (2nd Edition) (Voices That Matter)*. New Riders.

[196] United Nations, World Population Prospects: The 2010 Revision: http://www.un.org/en/development/desa/population/publications/pdf/trends/WPP2010/WPP2010_Volume-I_Comprehensive-Tables.pdf 2012-04-10

[197] Usability for Senior Citizens (Jakob Nielsen's Alertbox): http://district4.ifas.ufl.edu/Tech/TechPubs/Usability4Seniors.pdf Accessed: 2012-04-22.

[198] User experience definitions: http://www.allaboutux.org/ux-definitions: http://www.allaboutux.org/ux-definitions Accessed: 2014-04-24.

[199] User Experience Design (Semantic Studios): http://semanticstudios.com/user_experience_design/ Accessed: 2013-01-30.

[200] Vassallo, D. J., Hoque, F., Farquharson Roberts, M., Patterson, V., Swinfen, P., & Swinfen, R. (2001). An evaluation of the first year's experience with a low-cost telemedicine link in Bangladesh. In: *Journal of Telemedicine and Telecare*, 7(3), 125-138.

[201] Varshney, U. (2007). Pervasive Healthcare and Wireless Health Monitoring. In: *Mobile Networks and Applications*. 12(2-3), 113–127.

[202] Vincent, A., Kaelber, D.C., Kaelber, D.C., Pan, E., Shah, S., Shah, S.S., Johnston, D. and Middleton, B. (2008). A patient-centric taxonomy for personal health records (PHRs). In: *AMIA Annual Symposium Proceedings* (Vol. 2008, p. 763). American Medical Informatics Association.

[203] Wagner, P.J., Howard, S.M. and Bentley, D.R. (2010). Incorporating patient perspectives into the personal health record: implications for care and caring. In: *Perspectives in health information management/ AHIMA, American Health Information Management Association.*

[204] Wakefield, D.S., Kruse, R.L., Wakefield, B.J., Koopman, R.J., Keplinger, L.E., Canfield, S.M. and Mehr, D.R. (2012). Consistency of Patient Preferences About a Secure Internet-Based Patient Communications Portal: Contemplating, Enrolling, and Using. In: *American Journal of Medical Quality*. 27(6), 494–502.

[205] Wald, J.S.J., Middleton, B.B., Bloom, A.A., Walmsley, D.D., Gleason, M.M., Nelson, E.E., Li, Q.Q., Epstein, M.M., Volk, L.L. and Bates, D.W.D. (2004). A patient-controlled journal for an electronic medical record: issues and challenges. In: *Studies in Health Technology and Informatics*. pp. 1166–1170.

[206] Wang, M., Lau, C., Matsen, F.A. and Kim, Y. (2004). Personal Health Information Management System and its Application in Referral Management. In: *IEEE Transactions on Information Technology in Biomedicine*. 8(3), 287–297.

[207] Web Accessibility for Older Users: A Literature Review: http://www.w3.org/TR/2008/WD-wai-age-literature-20080514/ Accessed: 2012-10-26.

[208] What Killed Google Health? And What Does Its Untimely Demise Mean?: http://commonhealth.wbur.org/2011/07/killed-google-health. Accessed: 2012-12-04.

[209] Wherton, J., Sugarhood, P., Procter, R., Hinder, S. and Greenhalgh, T. (2015). Co-production in practice: how people with assisted living needs can help design and evolve technologies and services. In: *Implementation Science*. 10(1), 75–75.

[210] Wiesner, M. and Pfeifer, D. (2010). Adapting recommender systems to the requirements of personal health record systems. In: *Proceedings of the 1st ACM International Health Informatics Symposium* (pp. 410-414). ACM.

[211] Wildemuth, B. M., Blake, C. L., Spurgin, K., Oh, S., & Zhang, Y. (2006). Patients' perspectives on personal health records: An assessment of needs and concerns. In: *Critical Issues in eHealth Research*.

[212] Wilcox, L., Morris, D., Tan, D., Gatewood, J., & Horvitz, E. (2011). Characterizing

patient-friendly micro-explanationsof medical events. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 29-32). ACM.

[213] Winkelman, W.J. (2003). Overcoming Structural Constraints to Patient Utilization of Electronic Medical Records: A Critical Review and Proposal for an Evaluation Framework. In: *Journal of the American Medical Informatics Association*. 11(2), 151–161.

[214] World Health Organization 2007. *Global Age-Friendly Cities*. WHO.

[215] World Health Organization 2012. *Good Health Adds Life to Years*. World Health Organization.

[216] World Population Prospects - 2017 Revision: https://esa.un.org/unpd/wpp/Publications/Files/WPP2017_KeyFindings.pdf Accessed: 2017-08-16.

[217] Wright, A. et al. (2011). Randomized Controlled Trial of Health Maintenance Reminders Provided Directly to Patients Through an Electronic PHR. In: *Journal of General Internal Medicine*. 27(1), 85–92.

[218] Wuerdeman, L., Volk, L., Pizziferri, L., Tsurikova, R., Harris, C., Feygin, R., Epstein, M., Meyers, K., Wald, J.S., Lansky, D. and Bates, D.W. (2005). How accurate is information that patients contribute to their Electronic Health Record? In: *AMIA Annual Symposium Proceedings (Vol. 2005, p. 834).* American Medical Informatics Association.

[219] Xie, B. (2011). Experimenting on the impact of learning methods and information presentation channels on older adults'e-health literacy. In: *Journal of the American Society for Information Science and Technology*. 62(9), 1797–1807.

[220] Xie, B., Wang, M., Feldman, R. and Zhou, L. (2012). Exploring older and younger adults' preferences for health information and participation in decision making using the Health Information Wants Questionnaire (HIWQ). In: *Health Expectations*, 17(6), 795-808.

[221] Yin, R.K. (2010). *Qualitative Research from Start to Finish*. The Guilford Press.

[222] Young, I. (2011). *Mental Models*. Rosenfeld Media.

[223] Zahabi, M., Kaber, D.B. and Swangnetr, M. (2015). Usability and Safety in Electronic Medical Records Interface Design: A Review of Recent Literature and Guideline Formulation. In: *Human Factors: Journal of the Human Factors and Ergonomics Society*. 57(5), 805–834.

[224] Zhang, Y. and Fu, W.T. (2011). Designing consumer health information systems: what do user-generated questions tell us? In: *Foundations of Augmented Cognition. Directing the Future of Adaptive Systems*. pp. 536–545.

[225] Ziefle, M., Klack, L., Wilkowska, W. and Holzinger, A. (2013). Acceptance of Telemedical Treatments – A Medical Professional Point of View. In: *Lecture Notes in Computer Science*. Springer Berlin Heidelberg. 325–334.

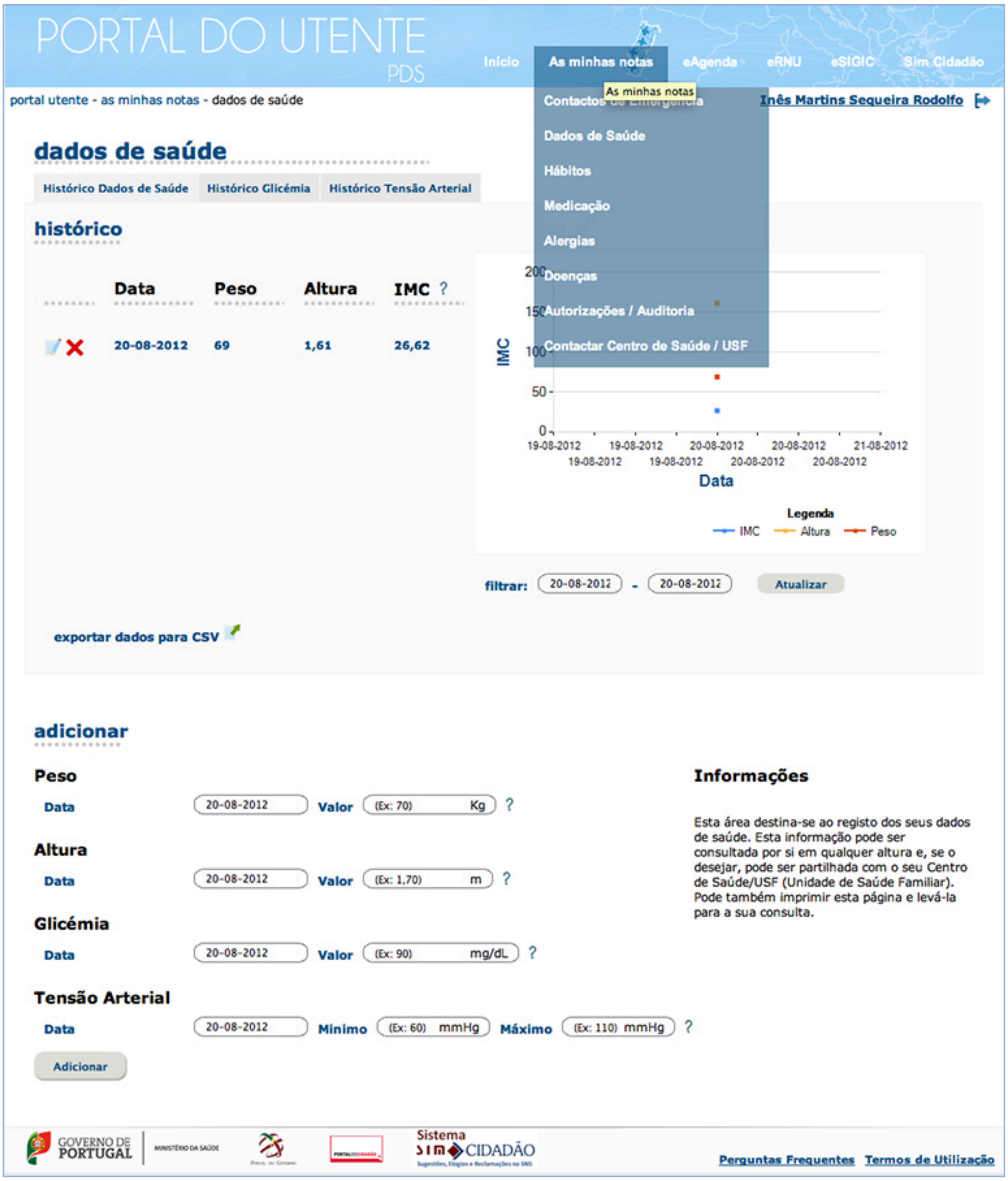
[226] Zieth, C.R., Chia, L.R., Roberts, M.S., Fischer, G.S., Clark, S., Weimer, M. and Hess, R. (2014). The Evolution, Use, and Effects of Integrated Personal Health Records: A Narrative Review. In: *Electronic Journal of Health Informatics*. 8(2), 17.

Appendix

A. Beta version of the Portuguese National Patient Portal

A.1 Home page beta version of the Portuguese National Patient Portal

A.2 Integrated PHR "Health data"



A.3 Integrated PHR User Interface for associating the citizen card

B. Stakeholders semi-structured interviews – Part 1

Portal do Utente / não autenticado - Stakeholders interviews

Compreender o estado actual do Portal do Utente (especial enfoque na parte não autenticada / página de entrada), visões futuras e estratégias a seguir. Reunir ideias e perspectivas dos stakeholders do projecto responsáveis pelas diferentes áreas de actuação (sponser e gestores do projecto, intervenientes do desenvolvimento, comunicação, marketing, relações públicas do produto e arquitectura da solução). Recolha de requisitos, conteúdos necessários e objectivos a alcançar.
Objectivo final: fornecer aos utilizadores do Portal do Utente uma experiência de utilização consistente.
Perceber o ciclo de vida do produto de forma a motivar utilizadores frequentes e atrair novos utilizadores.
Contribuição para a o bom funcionamento da Plataforma de Dados de Saúde e respectiva melhoria do Serviço Nacional de Saúde.

*Obrigatório

Participants data

Perguntas a serem respondidas por todos os entrevistados

1. **Nome do entrevistado** *

   ____

2. **Responsabilidade / Função** *
   Marcar apenas uma oval.

   ◯ Sponsor do Projecto
   ◯ Gestão da PDS
   ◯ Gestor do Produto
   ◯ Developer
   ◯ Business Intelligence Analyst
   ◯ Customer Support
   ◯ Marketing
   ◯ Outra: ____________________

3. **Projectos da PDS em que está envolvido** *
   Marcar tudo o que for aplicável.

   ☐ Portal do Utente
   ☐ Portal do Profissional
   ☐ Portal Institucional
   ☐ Portal Internacional

4. **Outros projectos em que está envolvido e que possam estar relacionados com a PDS**
   Pode existir informação cruzada entre portais

5. **Domínios de respostas** *
   Categorias de respostas indicadas por participante
   Marcar tudo o que for aplicável.
   - [ ] Product strategy
   - [ ] Marketing
   - [ ] Service & Content Design
   - [ ] User Experience
   - [ ] Product development & Solution architecture
   - [ ] Customer Support

A - Product strategy

6. **A1 - De que forma o Portal do Utente pode beneficiar o Serviço Nacional de Saúde?**

7. **A2 - Quais são os principais intervenientes envolvidos no ecosistema do produto?**
   prestadores de cuidados...centros de saúde...hospitais públicos

8. **A3 - O que pode ser melhorado para uma boa integração do Portal do Utente com a PDS?**

9. **A4 - Quais as principais necessidades que o portal de entrada deve responder e como criar valor para os seus utilizadores e intervenientes?**

10. **A5 - Que serviços dão exclusividade ao produto?**
    Ex: marcação online de consultas com o centro de saúde

11. **A6 - Seria vantajoso uniformizar todos ou alguns dos portais da PDS numa única plataforma de entrada multi-canal?**
Marcar apenas uma oval.

- Sim
- Não

12. **A7 - Se sim, que portais poderiam fazer parte desta integração e como poderia funcionar a sua estrutura multi-canal?**
Faça um zoom out para uma visão holistica e integrada da experiência da PDS para os seus interveninentes

13. **A8 - De forma a podermos incluir o grupo de utilizadores estrangeiros residentes em Portugal? Concorda com estas duas estratégias para o produto? Deseja incluir mais alguma?**
Seleccionar só com as quais concorda
Marcar tudo o que for aplicável.

- [ ] Opção multi-língua para estrangeiros pelo menos a língua inglesa
- [ ] Criação de conteúdo específico para estrangeiros no portal de entrada que demonstre o que é necessário para que este grupo de utilizadores se registe no portal, envolvendo toda a experiência que precede o registe no site (ex: registo junto do SNS)
- [ ] Outra:

14. **A9 - Relativamente à autenticação que estratégias estão a ser equacionadas para simplificar o processo de acesso com o cartão de cidadão?**

B - Marketing

15. **B1 - Pode dar alguns bons exemplos similares no mercado da saúde com o qual o portal poderá competir?**
Quais são os principais concorrentes do Portal do Utente?

16. **B2 - Na sua opinião, de que forma o Portal do Utente pode ser promovido?**
Que canais de comunicação devem ser utilizados?
Marcar tudo o que for aplicável.

- [ ] Através dos media TV e rádio
- [ ] Através do novos media das redes sociais
- [ ] Capanhas nas farmácias
- [ ] Campanhas nos Centros de Saúde
- [ ] Campanhas nos Hospitais Públicos
- [ ] Campanhas nos Hospitais privados
- [ ] Outras Campanhas
- [ ] Outra: ____________________

17. **B3 - Existe alguma campanha(s) que queira divulgar como exemplo de sucesso?**

____

18. **B4 - O que está a ser pensado para novas campanhas?**

____

19. **B5 - A promoção via web através da técnica word-of-mouth pelos embaixadores envolve a divulgação através das redes sociais?**
Como funciona? Qual o perfil mais adequado para os embaixadores?

____

C - Service & Content Design

Perguntas a serem respondidas por todos os entrevistados

20. **C1 - Dos actuais conteúdos do portal de entrada, quais podem ser retirados?**
(pode ser consultado o portal de entrada neste momento)
Marcar tudo o que for aplicável.

- [ ] Serviços
- [ ] Prestadores
- [ ] Dicionário do Utente
- [ ] Eventos
- [ ] Ajuda
- [ ] Nenhum

21. **C2 - Dos conteúdos que devem permanecer, quais podem ser simplificados?**
(pode ser consultado o portal de entrada neste momento)
Marcar tudo o que for aplicável.

- [ ] Serviços
- [ ] Prestadores
- [ ] Dicionário do Utente
- [ ] Eventos
- [ ] Ajuda
- [ ] Nenhum

22. **C3 - Justifique ambas as questões prévias**

23. **C4 - Dos actuais conteúdos do portal de entrada, quais necessitam de validação clínica?**
Marcar tudo o que for aplicável.

- [ ] Serviços
- [ ] Prestadores
- [ ] Dicionário do Utente
- [ ] Eventos
- [ ] Ajuda
- [ ] Nenhum

24. **C5 - De uma forma geral e sucinta, quais os principais serviços e funcionalidades que o portal de entrada deve oferecer?**

D - User Experience

25. **D1 - Quais são principais grupos de utilizadores e seus atributos?**
Funções e papéis desempenhados, dados demográficos

26. **D2 - Quais os principais contextos em que os grupos de utilizadores utilizam o produto?**
Descrever os principais cenários

27. **D3 - De que forma o portal de entrada pode trazer satisfação aos utentes e melhorar a sua experiência?**

28. **D4 - Na sua opinião, que estratégias no portal de entrada podem ser seguidas de forma a atrair novos utilizadores?**

29. **D5 - Como obter utilizadores regulares?**
(como motivar para essa regularidade)

30. **D6 - Quais as reacções mais desejadas na experiência de utilização do portal de entrada?**
Escolher as cinco reacções mais desejadas
Marcar tudo o que for aplicável.

- [ ] Acessível
- [ ] Apelativo
- [ ] Consistente
- [ ] Desejável
- [ ] Eficiente
- [ ] Cativante
- [ ] Expectável
- [ ] Amigável
- [ ] Intuitivo
- [ ] Significativo
- [ ] Motivante
- [ ] Responsivo
- [ ] Confiável
- [ ] Seguro
- [ ] Valioso
- [ ] Útil
- [ ] Outra: ____________

31. **D7 - Numa escala de 1 a 5 classifique o estado da terminologia e tom aplicados aos conteúdos actuais do portal**
Escolher as cinco reacções mais desejadas
Marcar apenas uma oval.

	1	2	3	4	5	
Linguagem muito técnica próxima de termos instituídos no SNS	○	○	○	○	○	Linguagem familiar e próxima do utente

E - Product development & solution architecture

32. **E1 - Na sua opinião, o que deve ser melhorado na versão actual do portal de entrada em termos de desenvolvimento?**

33. **E2 - Que conteúdos ou links rápidos a funcionalidades devem ter maior destaque na página de entrada?**

34. **E3 - Existe alguma funcionalidade CORE com grande potencial na experiência da PDS que não esteja a funcionar da melhor forma?**
Marcar apenas uma oval.

- SIm
- Não

35. **E4 - Se sim qual ou quais?**

36. **E5 - Para que plataformas desejam desenvolver no futuro?**
Marcar tudo o que for aplicável.

- [ ] Web responsivo
- [ ] iOS
- [ ] Android
- [ ] Windows phone

37. **E6 - Dos sitelinks existentes quais considera relevantes para aparecer abaixo do resultado de pesquisa no Google?**
Os links exibidos abaixo de alguns resultados de pesquisa do Google, chamados de links do site, têm como finalidade ajudar os usuários a navegar em seu site.
Marcar tudo o que for aplicável.

- [ ] Portal do Utente - registo
- [ ] Taxas moderadoras
- [ ] Isenção das taxas moderadoras
- [ ] Serviços
- [ ] Recuperação de senha
- [ ] Sobre este portal

38. **E7 - Existem outros sitelinks mais relevantes para aparecer abaixo do resultado de pesquisa no Google?**
Os links exibidos abaixo de alguns resultados de pesquisa do Google, chamados de links do site, têm como finalidade ajudar os usuários a navegar em seu site.

39. **E8 - Considera importante seguir as normas de acessibilidade da W3C?**
Marcar apenas uma oval.

- Sim
- Não

40. **E9 - Gostaria de dar alguns exemplos que possam inspirar o redesign do portal de entrada?**

F - Customer Support

41. **F1 - Qual a média de chamadas diárias dos utentes?**

42. **F1 - Quais as reacções negativas que maior reflectem os problemas reportados?**
(escolhidas a partir do microsoft reaction cards)
Marcar tudo o que for aplicável.

- [ ] Complexo
- [ ] Difícil de utilizar
- [ ] Inconsistente
- [ ] Pouco seguro
- [ ] Lento
- [ ] Imprevisível
- [ ] Demorado
- [ ] Esmagador (overwhelming)
- [ ] Frustrante
- [ ] Irritante

43. **F2 - Qual o grupo de utilizadores que mais entram em contacto com o apoio ao cliente?**
Marcar tudo o que for aplicável.

- [ ] Familiares de pessoas séniores (ex: filhos)
- [ ] Responsáveis pelo agregado familiar (ex: mãe)
- [ ] Até aos 30
- [ ] Dos 30 aos 60
- [ ] Dos 60 parca cima (séniores)

44. **F3 - Quais os principais problemas recorrentes enunciados pelos utentes durante as chamadas relativamente ao portal de entrada?**
(portal não autenticado)
Marcar tudo o que for aplicável.

- [ ] Registo do utilizador manual
- [ ] Registo de novo utilizador com cartão de cidadão
- [ ] Autenticação manual
- [ ] Autenticação com cartão de cidadão
- [ ] Procura do funcionamento dos serviços disponíveis no Portal do Utente (ex: cancelar uma consulta)
- [ ] Procura de contactos
- [ ] Procura de informação sobre as taxas moderadoras
- [ ] Dúvidas sobre a partilha de Informação clínica
- [ ] Outra: ____________________

45. **F3.1 - Existem outros menos frequentes que incluam os pedidos dos utentes para usufruirem de uma melhor experiência?**
(portal não autenticado)

____

46. **F4 - Quais os principais problemas de usabilidade reportados no processo de registo?**
Sign up (registar)

____

47. **F5 - Quais os principais problemas de usabilidade reportados no processo de autenticação?**
Log in (entrar)

____

48. **F6 - Quais os principais problemas de usabilidade reportados na navegação geral do portal de entrada?**

____

49. **F7 - A informação existente no portal de entrada reflecte os conteúdos e funcionalidades do portal autenticado?**
Se existe informação extra no portal de entrada que não existe dentro do autenticado
Marcar apenas uma oval.

- ( ) Sim
- ( ) Não

50. **F8 - Caso seja a resposta anterior seja não, que tipo de informação existe no portal de entrada que não esteja relacionada com os conteúdos e funcionalidades do portal autenticado?**

____

51. **F9 - Qual foi o impacto da mudança no apoio ao cliente quando a versão o portal mudou? Quanto tempo demorou a estabilizar?**

52. **F9 - De uma escala de 1 a 5 como classificaria a satisfação geral dos utentes?**
Marcar apenas uma oval.

	1	2	3	4	5	
Muito descontente	◯	◯	◯	◯	◯	Muito contente

53. **F10 - Como classifica a estrutura e organização da informação na ajuda?**
Marcar apenas uma oval.

	1	2	3	4	5	
Pouco eficaz	◯	◯	◯	◯	◯	Muito eficaz

Final Questions

54. **Na sua opinião, a partir de uma escala de 1 a 5, onde está o actual portal de entrada posicionado em termos de maturidade?**
Marcar apenas uma oval.

	1	2	3	4	5	
Pouco maduro	◯	◯	◯	◯	◯	Muito maduro

55. **Tem conhecimento de algum documento que contenha o levantamento de conteúdos da versão actual?**
Marcar apenas uma oval.

◯ Sim conheço
◯ Desconheço

56. **Existem outras sugestões ou dúvidas que não tenham sido abordadas?**

C. Card Sorting remote study

Study participant's welcome page

UNIVERSIDADE NOVA DE LISBOA

Bem-vindo

Muito obrigada, desde já, pela sua colaboração.

Este exercício surge no âmbito de um estudo acerca dos sistemas pessoais de informação de saúde. Mais precisamente, pretende ajudar na organização da informação presente no Portal do Utente (que integra a Plataforma Nacional de Dados de Saúde), no âmbito de uma colaboração entre a Universidade Nova de Lisboa e os Serviços Partilhados do Ministério da Saúde.

O objectivo deste exercício é optimizar o Portal do Utente para que a procura de informação no mesmo seja intuitiva, permitindo uma boa experiência aos seus utilizadores.

Uma maneira de compreender a melhor forma de organizar a informação é realizar este exercício que se chama "card sorting" (sorteio de cartas) sobre o qual contamos com a sua participação.

O exercício não durará mais que 10 a 15 minutos a completar. Os dados recolhidos são anónimos e confidenciais, e serão utilizados apenas para fins estatísticos, no âmbito do estudo referido anteriormente.

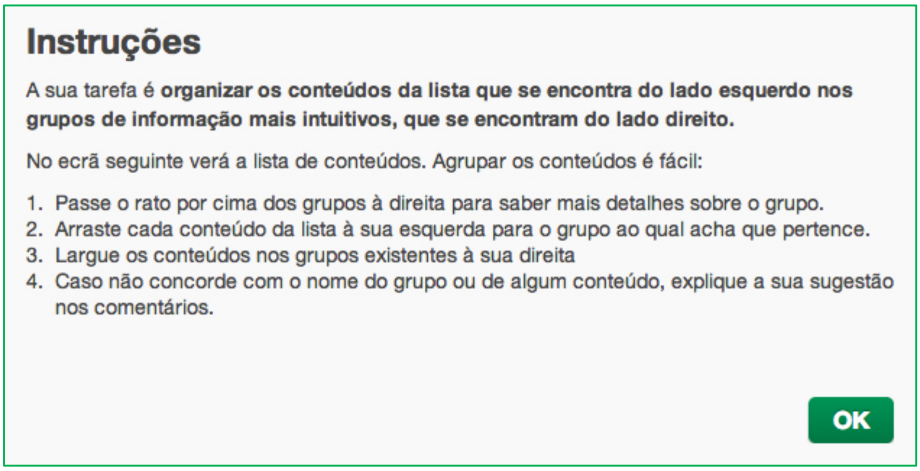
Se tiver dúvidas não hesite em contactar-nos!

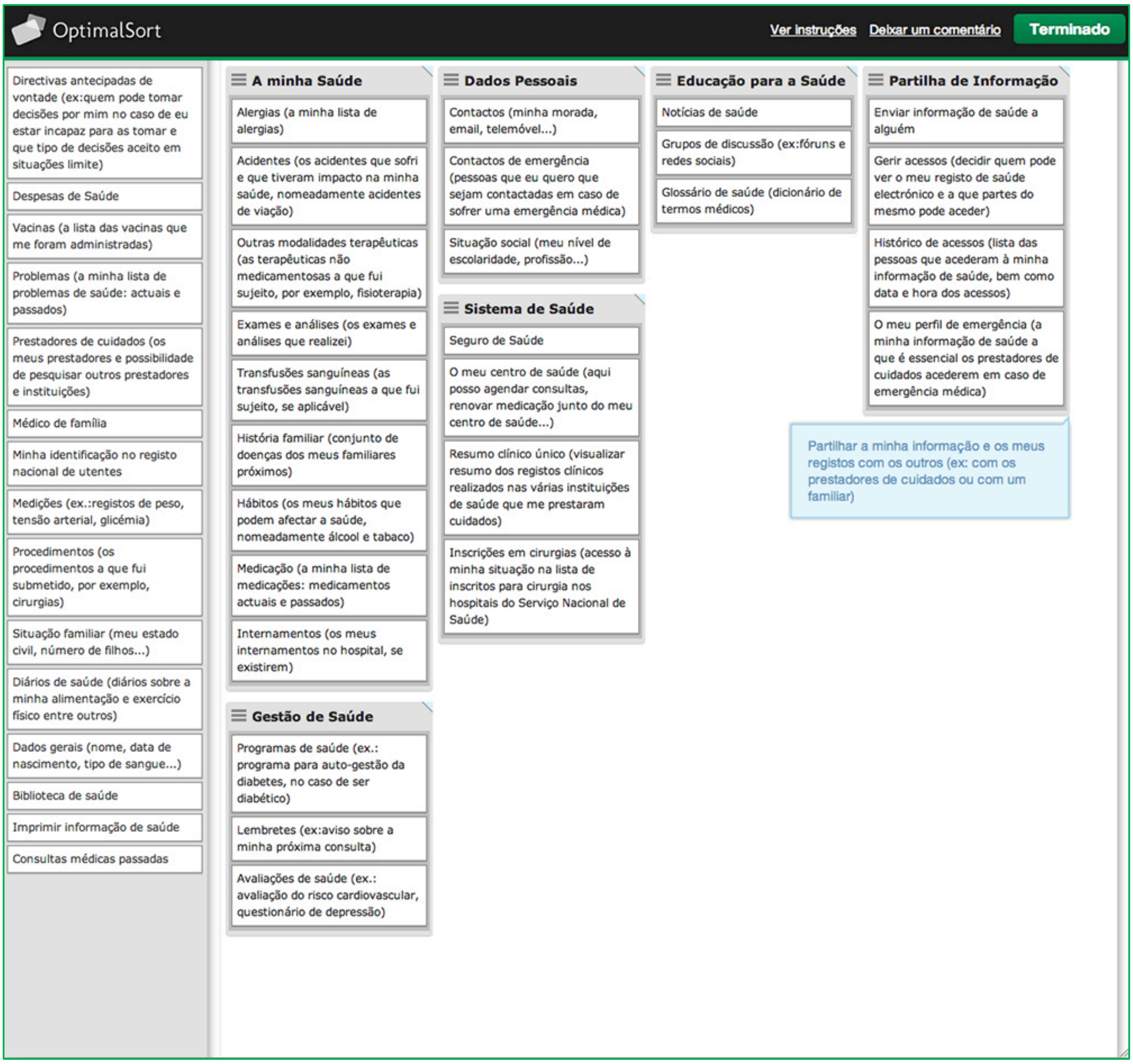
Obrigado pela sua participação!

O Grupo de Investigadoras: Inês Rodolfo e Liliana Laranjo / Contacto: imsrodolfo@gmail.com

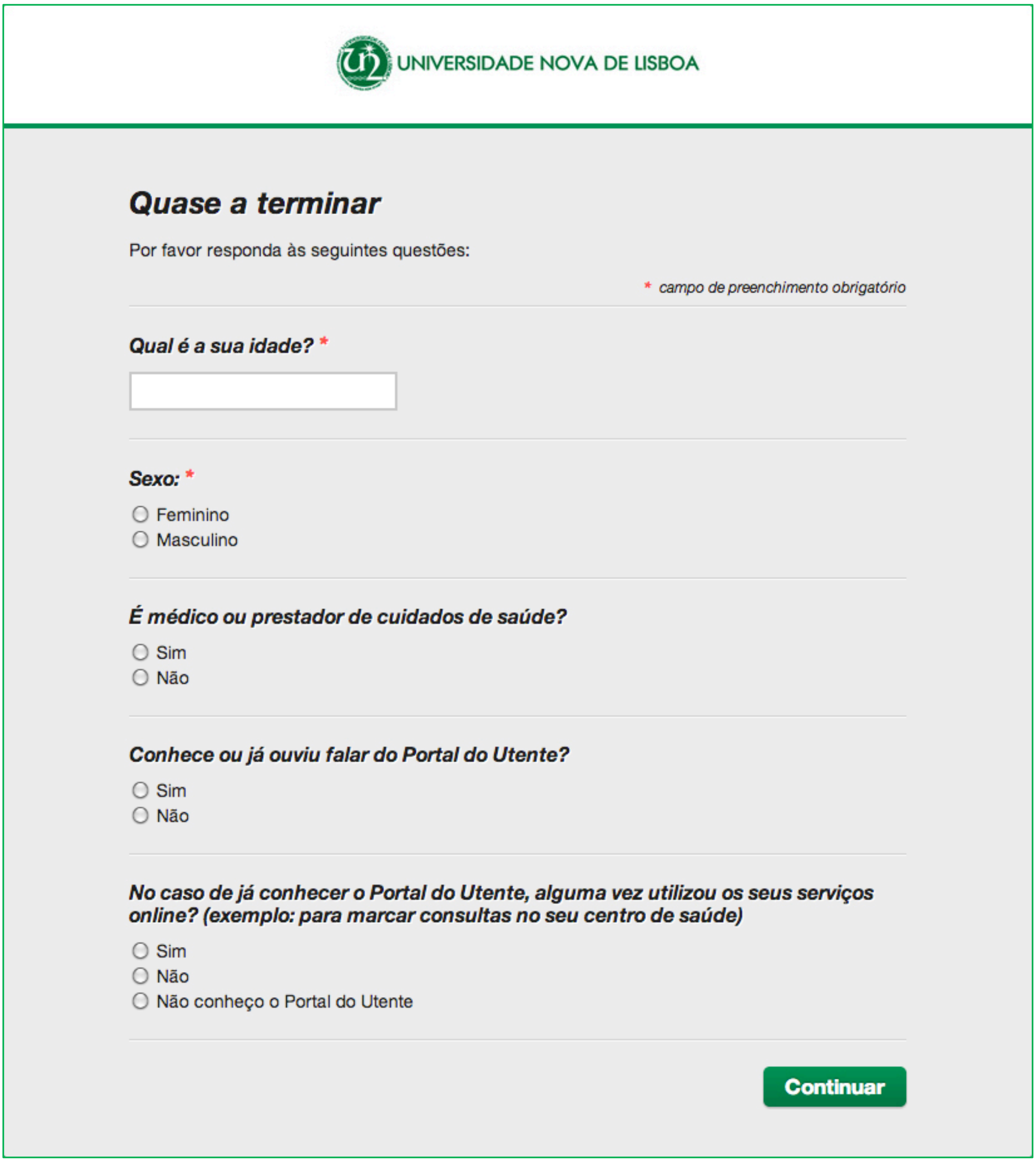
Continuar

Instructions and arrangement cards of one of the participants





Final short questionnaire



UNIVERSIDADE NOVA DE LISBOA

Quase a terminar

Por favor responda às seguintes questões:

* *campo de preenchimento obrigatório*

Qual é a sua idade? *

Sexo: *

- Feminino
- Masculino

É médico ou prestador de cuidados de saúde?

- Sim
- Não

Conhece ou já ouviu falar do Portal do Utente?

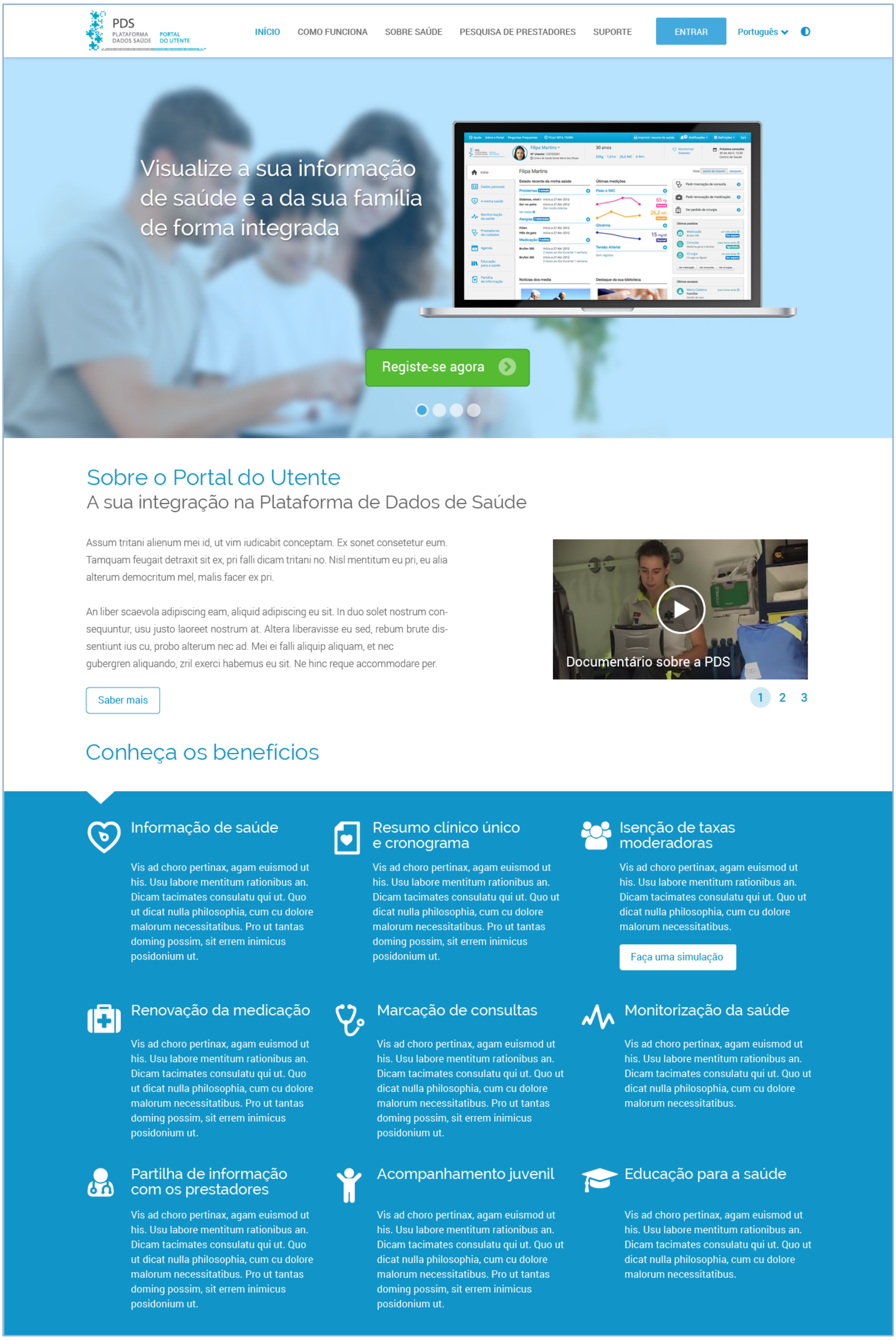
- Sim
- Não

No caso de já conhecer o Portal do Utente, alguma vez utilizou os seus serviços online? (exemplo: para marcar consultas no seu centro de saúde)

- Sim
- Não
- Não conheço o Portal do Utente

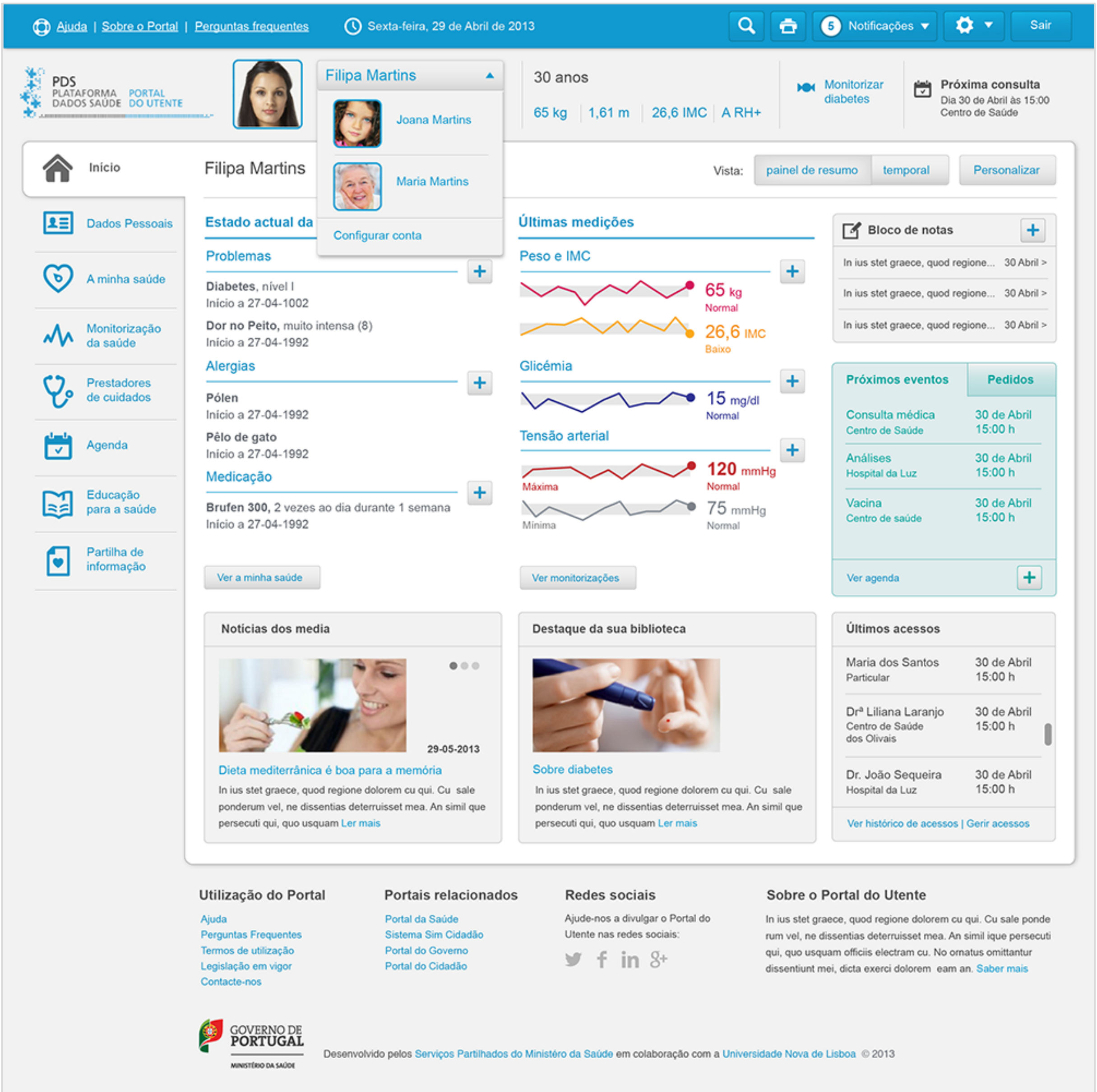
Continuar

D. Visual Design Proposal for the Patient Portal Public Area

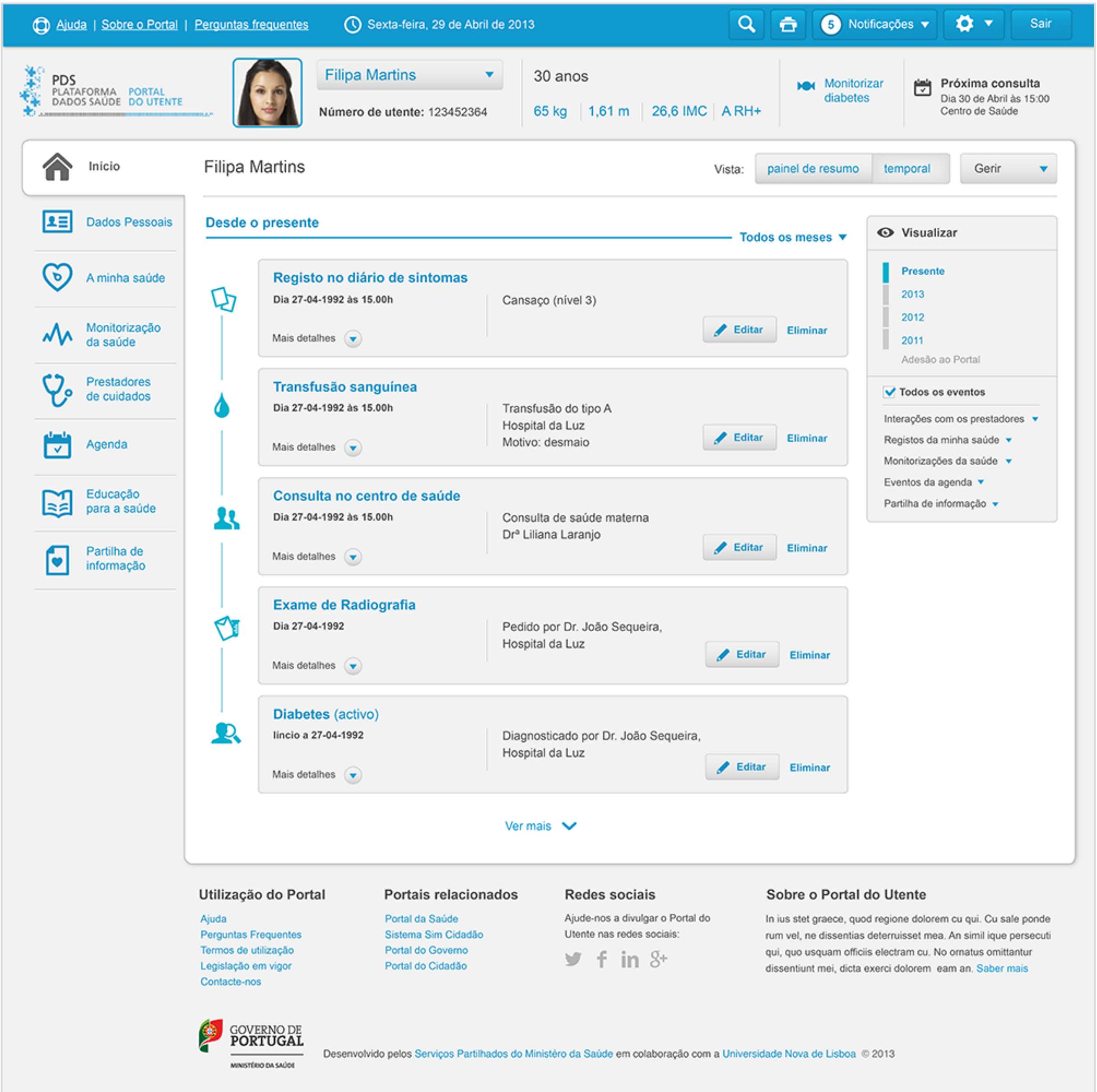


E. Visual Design Proposal for the Patient Portal Integrated PHR

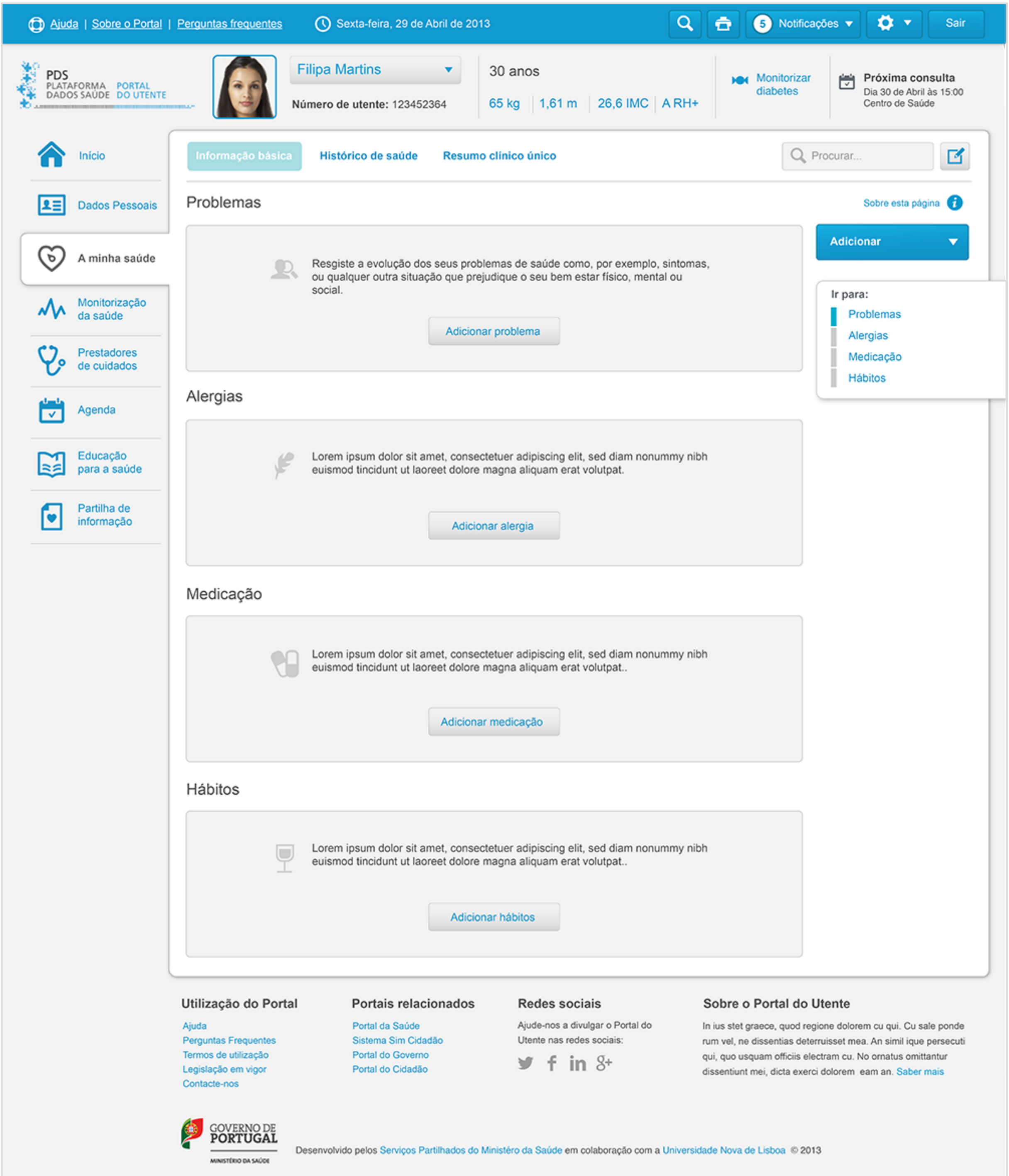
Summary dashboard view



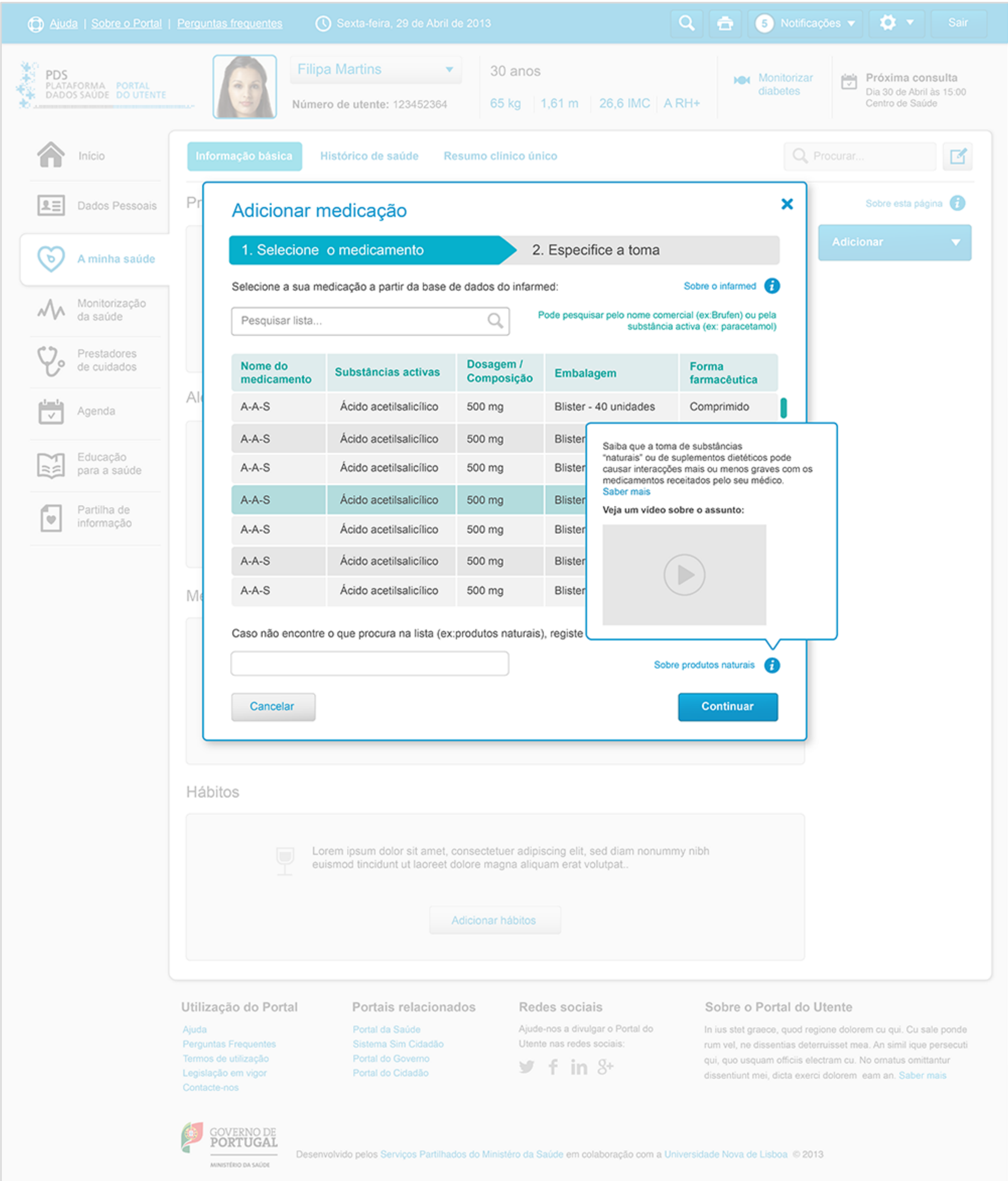
Timeline dashboard view



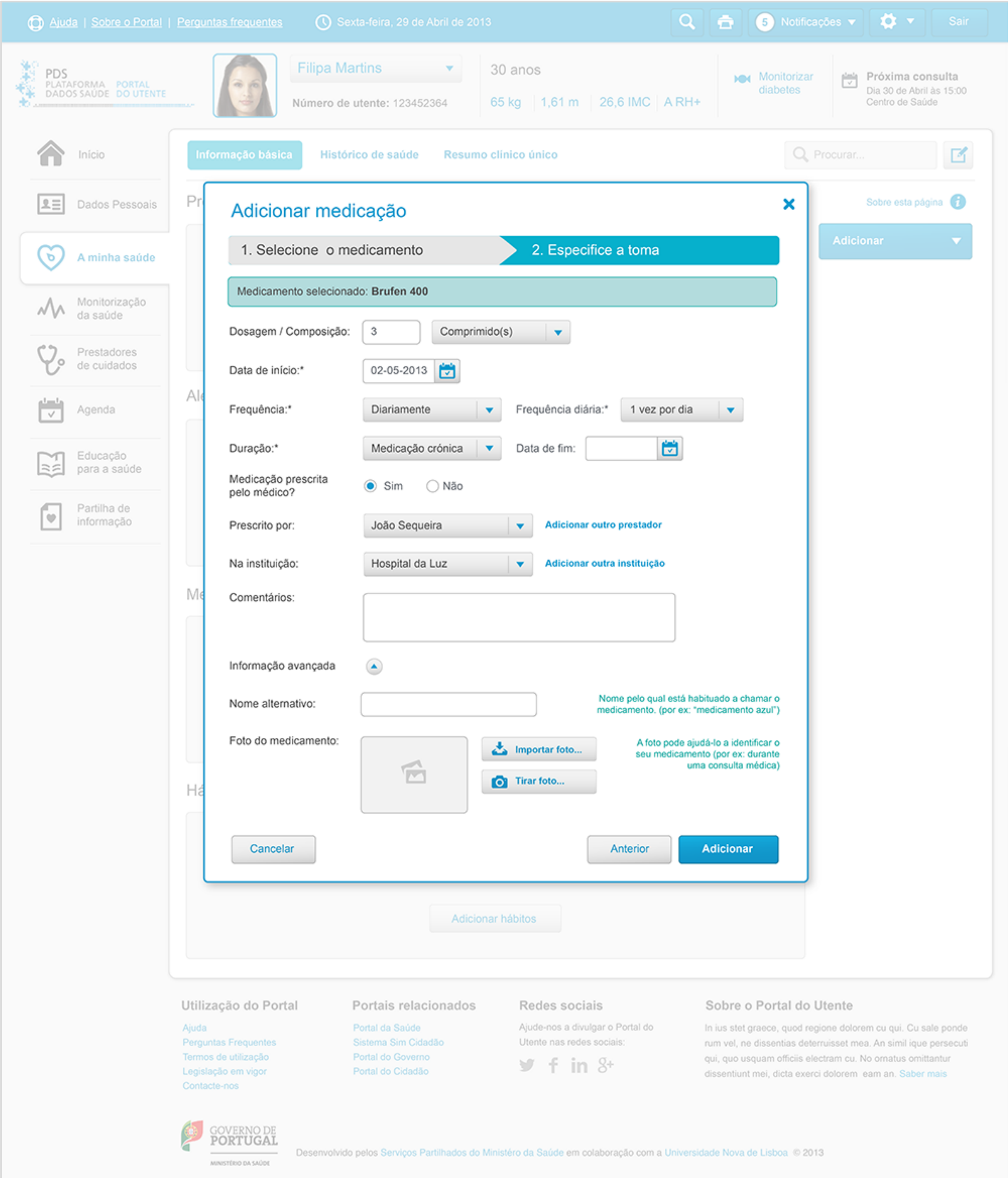
My Health (first time view)



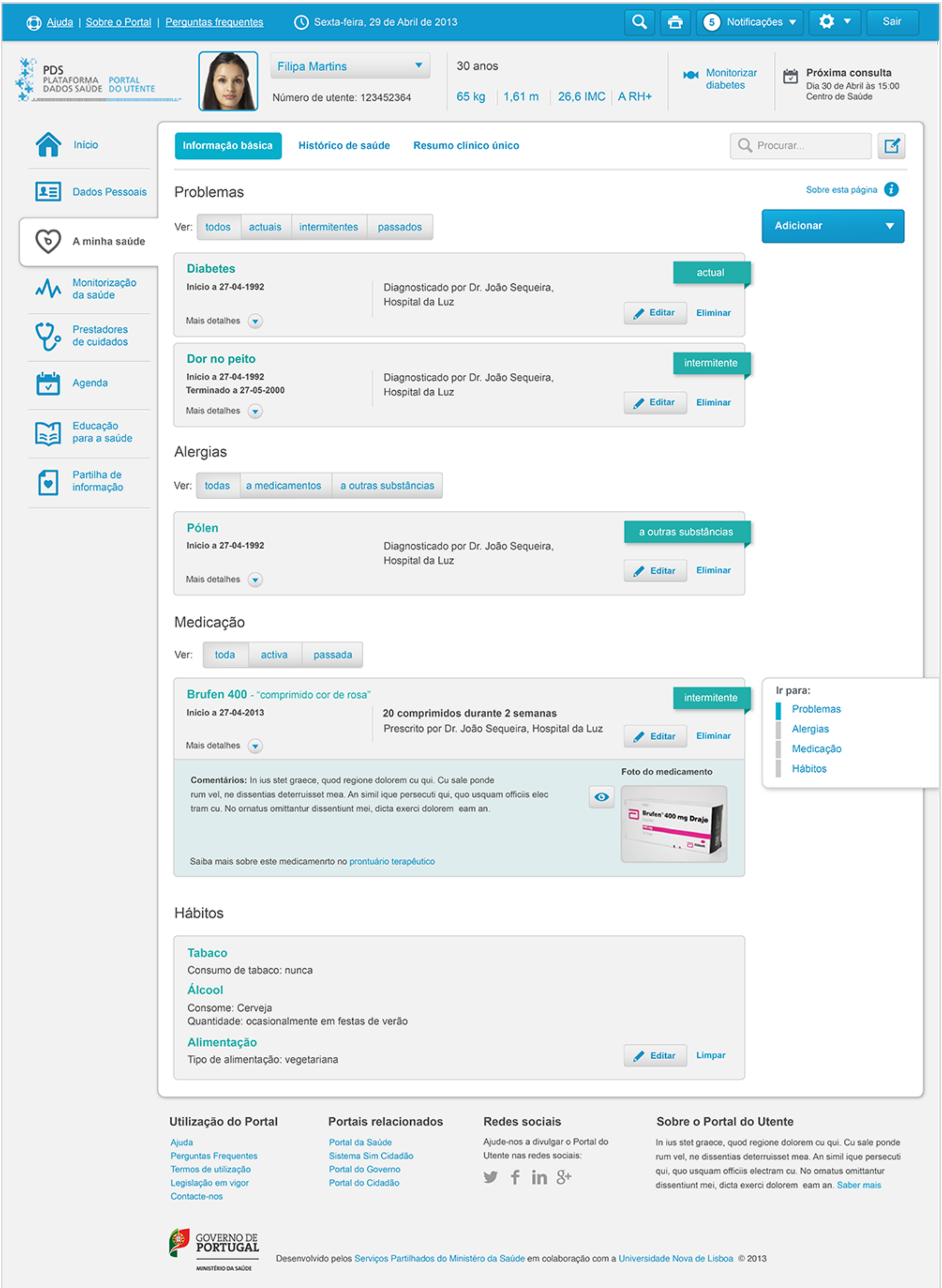
Adding a new medication: selection stage


Ajuda | Sobre o Portal | Perguntas frequentes
Sexta-feira, 29 de Abril de 2013
Notificações
Sair
PDS PLATAFORMA DADOS SAÚDE PORTAL DO UTENTE
Filipa Martins
Número de utente: 123452364
30 anos
65 kg 1,61 m 26,6 IMC A RH+
Monitorizar diabetes
Próxima consulta
Dia 30 de Abril às 15:00
Centro de Saúde
Início
Dados Pessoais
A minha saúde
Monitorização da saúde
Prestadores de cuidados
Agenda
Educação para a saúde
Partilha de informação
Informação básica
Histórico de saúde
Resumo clínico único
Procurar...
Sobre esta página
Adicionar
Adicionar medicação
1. Selecione o medicamento
2. Especifice a toma
Selecione a sua medicação a partir da base de dados do infarmed:
Sobre o infarmed
Pesquisar lista...
Pode pesquisar pelo nome comercial (ex:Brufen) ou pela substância activa (ex: paracetamol)
Nome do medicamento
Substâncias activas
Dosagem / Composição
Embalagem
Forma farmacêutica
A-A-S
Ácido acetilsalicílico
500 mg
Blister - 40 unidades
Comprimido
Saiba que a toma de substâncias "naturais" ou de suplementos dietéticos pode causar interacções mais ou menos graves com os medicamentos receitados pelo seu médico.
Saber mais
Veja um vídeo sobre o assunto:
Caso não encontre o que procura na lista (ex:produtos naturais), registe
Sobre produtos naturais
Cancelar
Continuar
Hábitos
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat..
Adicionar hábitos
Utilização do Portal
Ajuda
Perguntas Frequentes
Termos de utilização
Legislação em vigor
Contacte-nos
Portais relacionados
Portal da Saúde
Sistema Sim Cidadão
Portal do Governo
Portal do Cidadão
Redes sociais
Ajude-nos a divulgar o Portal do Utente nas redes sociais:
Sobre o Portal do Utente
In ius stet graece, quod regione dolorem cu qui. Cu sale ponde rum vel, ne dissentias deterruisset mea. An simil ique persecuti qui, quo usquam officiis electram cu. No omatus omittantur dissentiunt mei, dicta exerci dolorem eam an. Saber mais
GOVERNO DE PORTUGAL
MINISTÉRIO DA SAÚDE
Desenvolvido pelos Serviços Partilhados do Ministério da Saúde em colaboração com a Universidade Nova de Lisboa © 2013

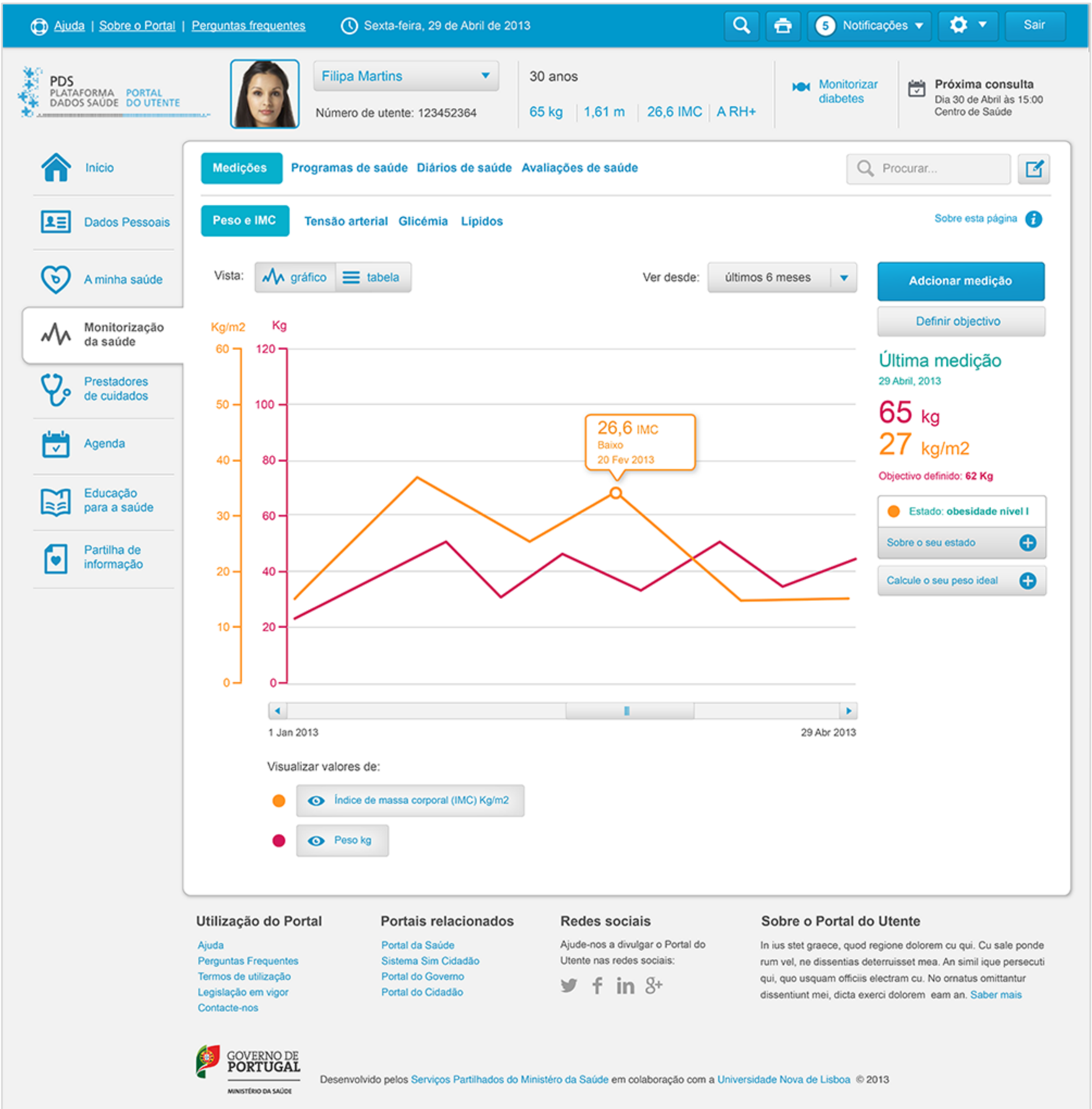
Adding a new medication: Medication take specification



My Health (fulfilled)



Health Monitoring



E. Semi-structured interviews – Part II

Estratégia (Administrador)

O objectivo do projecto MAB online relativamente ao programa Saúde 24 Sénior, é atingir um maior número de população sénior e atribuir um maior apoio à decisão clínica promovida pela LCS, ajudando a melhorar os atuais processos. É proposto que o canal online não só aplique o método de avaliação global do estado de saúde do sénior, para fins de triagem e de acompanhamento, mas que explore ferramentas de auto-preenchimento de saúde que ajudem a compreender a evolução do indivíduo ao longo do tempo, através uma periodicidade complementar ao canal telefónico. Estas ferramentas terão como base funcionalidades típicas de PHRs como medições ou diários, contemplando recomendações inteligentes e material educativo online (que telefonicamente não seria viável).

O workflow de integração de ambos os canais deve ser estudado de forma a disponibilizar conhecimento sobre o estado do indivíduo aos enfermeiros da LCS ajudando a optimizar a qualidade do tempo telefónico disponibilizado aos utentes.

Sobre o Programa Linha de Saúde 24 Sénior

1. **Qual o objectivo do Programa Linha de Saúde 24 Sénior?**
   Qual a relação / integração com os serviços do SNS?

2. **Em caso de encaminhamento, quais os principais serviços para onde são reencaminhados?**
   Exemplo: Qual a percentagem encaminhada para obtenção de cuidados médicos em centros de saúde?

3. **Como surgiu esta iniciativa?**

4. **Quantas pessoas estão a ser seguidas e como aderiram ao programa?**

5. **Qual a média de chamadas por dia totais (pela LCS) e média de primeiros contactos diários dos séniores?**

6. **De que forma são neste momento as pessoas séniores motivadas a aderirem ao programa?**

7. **O que pode ser melhorado no actual funcionamento do Programa?**

8. **No âmbito da comemoração recente do aniversário de Saúde 24 foi referido num possível futuro encaminhamento das chamadas telefónicas para um centro de saúde virtual através de video-chamada. No que consiste este projecto?**

Avaliação de um novo canal online

9. **Quais os benefícios de um possível canal online complementar ao canal telefónico e como deve funcionar a integração entre ambos?**
   Exemplo: Primeiras avaliações iniciais (atrair maior número de pessoas); atrair pessoas com problemas auditivos; disponibilizar os resultados das avaliações e respectivas recomendações inteligentes ao longo do tempo para que o próprio sénior tenha consciência do seu estado global e evolução ao longo do tempo.

10. **Considera relevante a disponibilização de material educativo quer de uma forma em geral, quer associado aos resultados das avaliações?**
    Exemplo: recomedações inteligentes geradas pelo PIC; links para sites educativos sobre saúde como as melhores práticas de auto-cuidados; imagens ilustrativas; dicionário de saúde ou blog de notícias

11. **Considera relevante a disponibilização de ferramentas de auto-monitorização (opcionais), complementares à avaliação MAB, de forma a atribuir ao programa maior informação reportada pelos seniores sobre a evolução da sua saúde ao longo do tempo?**
    Exemplo: Medições manuais como o peso ou tensão arterial, medições automáticas como sensores de quedas; diários de sintomas ou de humor; chat de comunicação com os enfermeiros sobre dúvidas.

Estratégia

12. **Em que contexto e de que forma podemos incentivar os seniores a aderirem ao canal online?**
    Como é que se poderia levar o sénior a preencher online? Devem ser referenciadas pelo canal telefónico? Pelos centros de saúde?

13. **Acha que o novo canal online poderá ajudar a optimizar a qualidade do tempo telefónico disponibilizado aos utentes?**

14. **Considera que o novo canal online poderá atribuir uma maior apoio à decisão clínica do Programa e melhorar os processos da LCS?**

15. **De que forma podemos assegurar a segurança e a protecção dos dados introduzidos pelos utentes?**

16. **Para que cenário(s) futuro(s) deseja o programa evoluir?**

Feedback Enfermeiros

O objectivo do projecto MAB online relativamente ao programa Saúde 24 Sénior, é atingir um maior número de população sénior e atribuir um maior apoio à decisão clínica promovida pela LCS, ajudando a melhorar os atuais processos. É proposto que o canal online não só aplique o método de avaliação global do estado de saúde do sénior, para fins de triagem e de acompanhamento, mas que explore ferramentas de auto-preenchimento de saúde que ajudem a compreender a evolução do indivíduo ao longo do tempo, através uma periodicidade complementar ao canal telefónico. Estas ferramentas terão como base funcionalidades típicas de PHRs como medições ou diários, contemplando recomendações inteligentes e material educativo online (que telefonicamente não seria viável).
O workflow de integração de ambos os canais deve ser estudado de forma a disponibilizar conhecimento sobre o estado do indivíduo aos enfermeiros da LCS ajudando a optimizar a qualidade do tempo telefónico disponibilizado aos utentes.

Performance das tele-chamadas do Programa Linha de Saúde 24 Sénior

1. **1. De uma forma geral, como funciona o programa de tele-chamada?**
   No sistema atual, quem é que inicia o processo de contacto telefónico: o enfermeiro ou o sénior.

2. **2. Qual é o tempo médio e periodicidade das chamadas telefónicas?**

3. **3. Qual é o perfil e contexto típico das pessoas que são acompanhadas no programa?**

4. **4. Como tem sido a sua experiência enquanto prestador de cuidados, de aplicar a avaliação MAB através do telefone?**

5. **5. Quais as principais dificuldades durante o registo do questionário ou durante o processo de interacção com os séniores, nas chamadas telefónicas?**

6. **6. Existem conceitos inerentes ao programa que não sejam compreendidos pelos séniores?**

7. **7. Qual tem sido o feedback dos séniores relativamente ao acompanhamento feito pelo programa?**

8. **8. De uma escala de 1 a 5 classifique a motivação / aderência dos participantes do programa.**
   Marcar apenas uma oval.

	1	2	3	4	5	
pouco motivado	◯	◯	◯	◯	◯	muito motivado

9. **9. Existem desistências? Se sim, quais os principais motivos?**

10. **10. Que melhorias ou necessidades reportam os participantes?**

11. **11. Os participantes encaram as recomendações (geradas pelo PIC) como uma mais valia?**

12. **12. Os participantes têm alguma dificuldade na memorização das recomendações?**

13. **13. Quais as principais dificuldades na gestão das chamadas?**

14. **14. O que pode ser melhorado a nível de operações / processos do programa?**

Avaliação de um novo canal online

15. **15. Quais os benefícios de um possível canal online complementar ao canal telefónico e como deve funcionar a integração entre ambos?**

16. **16. É relevante ser o próprio sénior a preencher?**
    Quais os benefícios de um possível auto-preenchimento do MAB?

17. **17. De que forma podemos incentivar os seniores a aderirem ao canal online?**
Como é que se poderia levar o sénior a preencher online? Deve notificar-se periodicamente o sénior?

18. **18. Acha que o preenchimento online poderia ser uma forma mais reservada / íntima ou cómoda de responder à avaliação?**

19. **19. Caso os seniores não possam responder, por incapacidade ou por falta de literacia digital, devemos incluir ou motivar os prestadores de cuidados informais como os familiares a ajudarem o preenchimento?**

PIC

20. **20. Que informação e feedback deverá o PIC oferecer aos séniores?**
(avaliar informação sensível que possa chocar as pessoas)

21. **21. Que tipo de material educativo poderá ser interessante para estar associado ao PIC, que telefonicamente não seria viável?**
Marcar tudo o que for aplicável.

- [ ] A. Recomendações inteligentes geradas pelo PIC descritas numa área específica facilmente consultável a qualquer momento pelo sénior
- [ ] B. Links para websites educativos sobre saúde (ex: melhores práticas sobre auto-cuidados, tratamentos...informação sobre problemas de saúde)
- [ ] C. Links para o apoio ao conhecimento do vocabulário médico
- [ ] D. Links para grupos de apoio de saúde online (ex: https://patient-innovation.com/)
- [ ] E. Links para oportunidades na participação em investigação médica
- [ ] F. Imagens ilustrativas (criadas pela LCS)
- [ ] G. Enciclopédia ou dicionário de saúde (criado pela LCS)
- [ ] H. Blog de notícias integrado no site (com conteúdos introduzidos pela LCS)
- [ ] Outra: ____________

22. **22. Que outras formas de visualização do PIC poderiam ser interessantes?**

Ferramentas complementares à avaliação (típicas de PHR)

23. **23. Que questões da avaliação poderão conter outras formas de edição online (que não são possíveis pelo telefone) de forma a oferecer uma maior detalhe à recolha de informação de saúde do utente?**

Ex: exercícios visuais que avaliam a cognição das pessoas (estado cognitivo); listas de classificação de doenças (doença crónica).

____

24. **24. Quais destas ferramentas características de PHRs poderão complementar o MAB online e oferecer um maior apoio à decisão clínica da LCS ?**

(como avaliações intermédias exclusivas do MAB online mas opcionais ao utente)

Marcar tudo o que for aplicável.

- [ ] A. Medição manual do peso
- [ ] B. Medição manual da tensão arterial
- [ ] C. Medição manual de glicémia
- [ ] D. Medições automáticas como sensores de quedas
- [ ] E. Diário de sintomas ou dor (descrições qualitativas dos sintomas que podem reportar níveis de dor através de escalas e duração)
- [ ] F. Diário de humor (reporta as emoções e estado de humor ao longo do tempo através de escalas)
- [ ] G. Diário do sono (medir a qualidade do sono através de uma escala)
- [ ] H. Diário de actividades de vida diária (AVD) ? já é o questionário….?
- [ ] Outra: ________________________

Conceptualização (médicos)

O objectivo do projecto MAB online relativamente ao programa Saúde 24 Sénior, é atingir um maior número de população sénior e atribuir um maior apoio à decisão clínica promovida pela LCS, ajudando a melhorar os atuais processos. É proposto que o canal online não só aplique o método de avaliação global do estado de saúde do sénior, para fins de triagem e de acompanhamento, mas que explore ferramentas de auto-preenchimento de saúde que ajudem a compreender a evolução do indivíduo ao longo do tempo, através uma periodicidade complementar ao canal telefónico. Estas ferramentas terão como base funcionalidades típicas de PHRs como medições ou diários, contemplando recomendações inteligentes e material educativo online (que telefonicamente não seria viável).
O workflow de integração de ambos os canais deve ser estudado de forma a disponibilizar conhecimento sobre o estado do indivíduo aos enfermeiros da LCS ajudando a optimizar a qualidade do tempo telefónico disponibilizado aos utentes.

Avaliação de um novo canal online

1. **1. Quais os benefícios de um possível canal online complementar ao canal telefónico e como deve funcionar a integração entre ambos?**

2. **2. É relevante ser o próprio sénior a preencher?**
   Quais os benefícios de um possível auto-preenchimento do MAB?

3. **3. De que forma podemos incentivar os seniores a aderirem ao canal online?**
   Como é que se poderia levar o sénior a preencher online? Deve notificar-se periodicamente o sénior?

4. **4. Em que contexto as pessoas devem aceder ao canal online?**
   Devem ser referenciadas pelo canal telefónico? Recomendadas pelos centros de saúde?

5. **5. Acha que o preenchimento online poderia ser uma forma mais reservada / íntima ou cómoda de responder à avaliação?**

6. **6. Caso os seniores não possam responder, por incapacidade ou por falta de literacia digital, devemos incluir ou motivar os prestadores de cuidados informais como os familiares a ajudarem o preenchimento?**

Aplicação do MAB online

7. **7. Caso a primeira avaliação seja feita online, faz sentido realizar o D2 após o D1, de forma a agilizar o processo de avaliação?**

8. **8. Nas avaliações subsequentes online de que forma é que se devem integrar os contactos telefónicos?**

9. **9. Qual a periodicidade recomendada para o D1 online?**

10. **10. Em caso de ocorrer o D2, qual a periodicidade recomendada online?**

11. **11. Com o objectivo de atribuir um maior apoio ao acompanhamento do sénior, qual o feedback desejado após os auto-preenchimentos online?**
    (ex: Faz sentido disparar alerta logo após o preenchimento? Se sim, para quem seria dirigido o alerta: médicos, enfermeiros da saúde 24 ou familiares; e em que condições deve ir para cada um dos intervenientes.)

PIC

12. **12. Que informação e feedback deverá o PIC oferecer aos séniores?**
    (avaliar informação sensível que possa chocar as pessoas)

13. **13. Que tipo de material educativo poderá ser interessante para estar associado ao PIC, que telefonicamente não seria viável?**
Marcar tudo o que for aplicável.

- [ ] A. Recomendações inteligentes geradas pelo PIC descritas numa área específica facilmente consultável a qualquer momento pelo sénior
- [ ] B. Links para websites educativos sobre saúde (ex: melhores práticas sobre auto-cuidados, tratamentos...informação sobre problemas de saúde)
- [ ] C. Links para o apoio ao conhecimento do vocabulário médico
- [ ] D. Links para grupos de apoio de saúde online (ex: https://patient-innovation.com/)
- [ ] E. Links para oportunidades na participação em investigação médica
- [ ] F. Imagens ilustrativas (criadas pela LCS)
- [ ] G. Enciclopédia ou dicionário de saúde (criado pela LCS)
- [ ] H. Blog de notícias integrado no site (com conteúdos introduzidos pela LCS)
- [ ] Outra: ________________

14. **14. Que outras formas de visualização do PIC poderiam ser interessantes?**

____

Ferramentas complementares à avaliação (típicas de PHR)

15. **15. Que questões da avaliação poderão conter outras formas de edição online (que não são possíveis pelo telefone) de forma a oferecer uma maior detalhe à recolha de informação de saúde do utente?**
Ex: exercícios visuais que avaliam a cognição das pessoas (estado cognitivo); listas de classificação de doenças (doença crónica).

____

16. **16. Quais destas ferramentas características de PHRs poderão complementar o MAB online e oferecer um maior apoio à decisão clínica da LCS ?**
(como avaliações intermédias exclusivas do MAB online mas opcionais ao utente)
Marcar tudo o que for aplicável.

- [ ] A. Medição manual do peso
- [ ] B. Medição manual da tensão arterial
- [ ] C. Medição manual de glicémia
- [ ] D. Medições automáticas como sensores de quedas
- [ ] E. Diário de sintomas ou dor (descrições qualitativas dos sintomas que podem reportar níveis de dor através de escalas e duração)
- [ ] F. Diário de humor (reporta as emoções e estado de humor ao longo do tempo através de escalas)
- [ ] G. Diário do sono (medir a qualidade do sono através de uma escala)
- [ ] H. Diário de actividades de vida diária (AVD) ? já é o questionário….?
- [ ] Outra: ________________

Feedback Séniores

O objectivo deste estudo relativamente ao programa Saúde 24 Sénior, é atingir um maior número de população sénior e melhorar os actual programa. É proposto de desenvolvimento de um acesso pela internet através de um canal online, que aplique não só as avaliações de acompanhamento mas que explore ferramentas de auto-preenchimento de saúde que ajudem a compreender a evolução do indivíduo ao longo do tempo, complementar ao canal telefónico. Estas ferramentas terão como base ferramentas como medições ou diários de saúde, recomendações inteligentes e material educativo online (que telefonicamente não seria viável).

Dados demográficos

1. **Idade**

   ____

2. **Sexo**
   Marcar apenas uma oval.
   - Feminino
   - Masculino

3. **Nível de escolaridade**
   Marcar apenas uma oval.
   - Básico
   - Secundário
   - Superior

4. **Estado civil**
   Marcar apenas uma oval.
   - Solteiro(a)
   - Casado(a)
   - Viúvo(a)

5. **Área de residência**

   ____

6. **Vive sozinho?**
   Marcar apenas uma oval.
   - Sim
   - Não, vivo acompanhado

7. **Tem filhos?**
   Marcar apenas uma oval.
   - Sim
   - Não

Experiência de adesão ao Programa Linha de Saúde 24 Sénior

8. **1. Como aderiu ao Programa Linha de Saúde 24 Sénior?**

9. **2. Como tem sido a sua experiência relativamente às chamadas telefónicas?**

10. **3. Classifique a sua experiência de adesão ao Programa**
Marcar apenas uma oval.

	1	2	3	4	5	
pouco positiva	◯	◯	◯	◯	◯	muito positiva

11. **4. Considera que tem sido importante o contacto com a linha de saúde 24 sénior?**

12. **5. O número de vezes que o contactam parece-lhe adequado?**

13. **6. Qual o impacto que tem tido na sua saúde ou bem-estar?**

14. **7. Sente-se confortável em responder ao questionário pelo telefone ou preferia outro meio?**
Se sim, qual?

15. **8. Gosta de ser acompanhado pela mesma pessoa ou é indiferente?**

16. **9. Após a avaliação que lhe é feita, costuma registar as recomendações ou memorizar?**
Se regista, de que forma?
Marcar apenas uma oval.

◯ Memorizo
◯ Registo no papel
◯ Registo no computador

17. **10. As recomendações têm sido úteis para si?**
(Após os contactos telefónicos tem facilidade em recordar as recomendações?)

18. **11. Gostaria que algum dos seus familiares tivesse acesso aos resultados das avaliações que são realizadas pelo telefone?**
por motivos de acompanhamento do estado de saúde

Avaliação de potencial adesão a um novo canal online complementar

19. **12. Costuma utilizar o computador?**
Se sim, para que fins? Utiliza por exemplo o Facebook? e email?

20. **13. Estaria disposto a fazer um auto-preechimento do mesmo questionário que lhe fazem pelo telefone, pela internet?**
(mesmo que seja algum familiar a ajudá-lo a preencher por si?)
Marcar apenas uma oval.

- Sim
- Não

21. **14. Acha que o preenchimento online poderia ser uma forma mais reservada / íntima ou cómoda de responder à avaliação?**
(mesmo que seja algum familiar a ajudá-lo a preencher por si?)
Marcar apenas uma oval.

- Sim
- Não
- É indiferente

22. **15. Gostaria de ter acesso aos resultados das suas avaliações, de uma forma segura, através da internet?**
Marcar apenas uma oval.

- Sim
- Não

23. **16. Gostaria de ter acesso às recomendações que lhe são feitas, de uma forma segura, através da internet?**
Marcar apenas uma oval.

- Sim
- Não

24. **17. Gostaria de ter acesso a material multimédia sobre saúde, relacionado com tópicos interessantes para si, fornecido pelos médicos /enfermeiros do programa?**
Se sim quais estaria interessado?
Marcar tudo o que for aplicável.

- [ ] A. Recomendações inteligentes de acordo com o seus problemas
- [ ] B. Links para websites educativos sobre saúde (ex: melhores práticas sobre auto-cuidados, tratamentos...informação sobre problemas de saúde)
- [ ] C. Links para o apoio ao conhecimento do vocabulário médico
- [ ] D. Links para grupos de apoio de saúde online (ex: https://patient-innovation.com/)
- [ ] E. Links para oportunidades na participação em investigação médica
- [ ] F. Imagens ilustrativas (criadas pela LCS)
- [ ] G. Enciclopédia ou dicionário de saúde (criado pela LCS)
- [ ] H. Blog de notícias integrado no site (com conteúdos introduzidos pela LCS)
- [ ] Outra: ____________________

25. **18. Caso aderisse ao canal online, gostaria de tirar partido de ferramentas de auto-monitorização como a medição do seu peso ou tensão arterial, para que depois os prestadores de cuidados conheçam melhor a sua e evolução no dia a dia?**
Marcar apenas uma oval.

- ( ) Sim
- ( ) Não

26. **19. Gostaria de partilhar a sua informação registada online com algum dos seus familiares?**
Para que possam estar a par do seu estado de saúde...
Marcar apenas uma oval.

- ( ) Sim
- ( ) Não

F. MAB Self-Assessment Questions

Auto-avaliação MAB

1 - Em que dia da semana estamos?
Atribuir datas aleatórias.

Certo/Errado

2 – No último mês, tem entendido o que lhe dizem, sem problemas?

Sim/Não

3 – No ultimo mês, teve alguma companhia ou esteve sozinho?

Com companhia/Sozinho

4 – No último mês, teve alguém com quem possa falar, ou, se necessário, pedir ajuda?

Sim/Não

5 – No último mês, necessitou de ajuda para andar em casa ou para se levantar da cadeira / sofá?

Sim/Não
--
Se sim:
Que tipo de ajuda utilizou?

- Utilizei meios de apoio (ex.: bengala, outros)
- Recorri a pessoas
- Não me levantei ou andei

6 – No último mês, necessitou de ajuda para realizar a sua higiene pessoal?
Exemplo: utilizar casa de banho, tomar banho....

Sim/Não
--
Se sim:
Que tipo de ajuda utilizou?

- Utilizei meios de apoio (ex.: calçadeira, atacadores elásticos, outros)
- Recorri a pessoas
- Não fiz a minha higiene

7 – No último mês, necessitou de ajuda para realizar as suas atividades do dia-a-dia?

Sim/Não
--
Se sim:
Que tipo de ajuda utilizou?

- Utilizei meios de apoio (ex.: contrato serviços, outros)
- Recorri a pessoas
- Não realizei as atividades

8 – Precisa de usar óculos para as suas atividades do dia-a-dia?

Sim/Não

9 – Precisa de usar aparelho para ouvir nas suas atividades do dia-a-dia?

Sim/Não

10 – Semanalmente, faz atividades que impliquem atividade física?

Sim/Não
--
Se sim:
Quanto tempo por semana, no total?
- 4 ou mais horas semanais (mais de 30 min por dia)
- Entre 2 a 4 horas semanais (menos de 30 min por dia)
- Menos de 2 horas semanais (menos de 15 min por dia)

11 – Que refeições toma habitualmente por dia?
- Pequeno-almoço
- Almoço
- Jantar
- Outras (vários snacks ao longo do dia)
- Meio da Manhã
- Lanche Ceia

12 – No último mês tem comido fruta ou produtos hortícolas?

Sim / Não

13 - Tem tido queixas ou problemas de saúde?

Sim/Não
--
Se sim:
Selecione por área de sistemas: (manter a escolha múltipla)
- Aparelho Digestivo
- Olho
- Ouvido
- Aparelho Circulatório
- Músculo-esquelético
- Sistema Nervoso
- Aparelho Respiratório
- Pele
- Endócrino/metabólico/nutricional
- Aparelho Urinário
- Aparelho Genital
- Sangue e órgãos hematopoiéticos
- Desconheço a área correspondente

14 - Toma medicamentos regularmente, de forma adequada?

Sim/Não

15 - Como classificaria a sua saúde comparando-a com pessoas da sua idade ou sexo?

Melhor/Idêntica/Pior

16 – Fuma ou está sujeito a ambiente com fumo?

Sim/Não

17 – Consome vinho às refeições ou consome outras bebidas alcoólicas?

Sim/Não
--
Se sim:
Quantos copos por dia?
- 1 copo por dia
- 2 ou mais copos por dia

18 – Caiu alguma vez, no último ano?

Sim/Não
--
Se sim:
Qual o número to tal de quedas?
- 1 queda
- 2 ou mais quedas

19 – No último mês, abandonou muitos dos seus interesses e atividades?

Sim/Não

20 – No último mês, de noite, tem dormido menos horas que o habitual?

Sim/Não

21 – Qual o seu peso atual?

Componente de inserção do peso

22 – Qual a sua altura?

Componente de inserção da altura

G. Usability Testing Script

Guião Testes de Usabilidade (avaliação UX)

Realizar pré-questionário ao telefone para simular a uma última avaliação.
Duração prevista 45 min a 1 hora.
Colocar relógio no momento da tarefa da monitorização.

(Subjective measures) de 1 (discorcordo fortemente) a 5 (concordo fortemente)

#1 Definir o perfil do utilizador

Tarefa 1.0 (direct task) – definir o perfil do utilizador
Para nos ajudar a personalizar o seu perfil de utilizador no programa, responda às questões que vão sendo apresentadas no ecrã.

#2 Explorar o dashboard de entrada

Tarefa 2.1 (open-ended, exploratory task) – explorar o dashboard de entrada
Imagine que tem estado a ser acompanhado pela Saúde 24 Sénior e que a informação disponível neste ecrã de entrada, refelete a interação com o programa.
Gostaríamos de lhe pedir, que faça uma leitura do ecrã e que descreva em voz alta o está a visualizar.

1. *Considera este resumo de entrada útil, no enquadramento do programa? (1-5)*
2. *Considera este resumo de entrada fácil de compreender? (1-5)*

Tarefa 2.2 (open-ended, exploratory task) – explorar o dashboard de entrada
Gostaríamos de lhe pedir, que aceda à outra vista desse mesmo ecrã, designada por monitorização.

Nesta vista, os conteúdos apresentados são simulados e apresentam um resumo sobre o que seria a monitorização dos seus dados de saúde (dar exemplos) através da aplicação.
Gostaríamos de lhe pedir que faça uma leitura do ecrã e que descreva em voz alta o está a visualizar.
Explicação posterior sobre os objectivos diários negociados com os enfermeiros do programa e recordes de saúde 24 e restantes funicionalidades apresentadas no ecrã.

1. *Acharia interessante, establecer objectivos diários com o enfermeiro, acordados nas chamadas quinzenais ou mensais e monitorizá-los através desta aplicação? (S/N)*
2. *Gostaria de aderir aos Recordes da Saúde 24 (explicar no que consiste) e visualizar o seu posicionamento na lista, dentro do grupo dos outros participantes inscritos no programa? (S/N)*
3. *Acha que esta funcionalidade poderia ser um estímulo não só para colocar os objectivos em prática como para ajudar a combater o isolamento social de algumas pessoas? (1-5)*
4. *Seria útil para si saber semanalmente (através da medição de um relógio inteligente), se tem tido uma vida ativa ou sedentária? (sabendo quantas horas de actividade física seriam necessárias para estar ativo) (S/N)*

Tarefa 2.3 (direct task)
Regresse à vista anterior sobre o resumo do seu plano de cuidados.
Responda à notificação que aparece na barra de topo da aplicação.

Considera relevante partilhar esporadicamente, como se sente, com os enfermeiros que o acompanham na Saúde 24?(S/N)

#3 Aceder à última avaliação

Tarefa 3.1 (direct task + exploratory) – aceder às avaliações / última avaliação
Aceda agora às suas avaliações.
Gostaríamos de lhe pedir que faça uma leitura do gráfico e descreva em voz alta o está a visualizar.

Tarefa 3.2 (A/B testing) – testar visualização da informação dos gráficos
Gostaríamos de lhe pedir que aceda a uma segunda alternativa ao gráfico apresentado (gráfico B).

Comparando este gráfico com o anterior,

1. *Qual considera mais compreensível (fácil leitura)? (A ou B)*
2. *Qual considera mais atrativo? (A ou B)*

Gostaríamos de lhe pedir que faça uma leitura do restante ecrã e que descreva em voz alta o está a visualizar. (pedir para fazer scroll down)
NOTA: as seguintes tarefas poderão ser open-ended, na medida em que a interação com a interface poderá ir acontecendo de forma natural, enquanto o participante explora e descreve em voz alta a interface.

Tarefa 3.3 (direct task) – colocar um comentário

Acha relevante, ser dada a possibilidade de fazer algum comentário ou apresentar alguma questão, relativa à avaliação que lhe foi feita pelo profissional de saúde? (S/N)

Como realizaria tal tarefa?

Acha que sendo dada a possibilidade de imprimir a avaliação, gostaria de utilizar esta funcionalidade para imprimir a avaliação para apresentar numa próxima consulta? Seria útil para si?] (S/N)

Tarefa 3.4 (scenario task) – colocar as recomendações em prática
Imagine o seguinte cenário: No último contato telefónico que teve com a Saúde 24 Sénior, após o enfermeiro ter dado algumas recomendações durante a vossa conversão, pediu-lhe que até ao próximo telefonema, aceda a esta área, de forma a partilhar se tem sido possível ou não, colocar em prática as recomendações.
Onde realizaria tal tarefa?

Considera que esta funcionalidade seja útil, tanto para si, como para os enfermeiros? (S/N)

Tarefa 3.5 (scenario task) – apreciar a qualidade do atendimento
Na sequência do cenário anterior, o enfermeiro durante a última chamada também lhe pediu para dar feedback quanto à utilidade do acompanhamento.
Onde realizaria tal tarefa?

Considera que esta funcionalidade seja útil, tanto para si, como para os enfermeiros? (S/N)

Perguntas finais

1. *É fácil perceber de uma forma rápida, o seu estado de saúde global? (1-5)*
2. *A forma de visualização da informação é estimulante? (1-5)*
3. *Consegue compreender o funcionamento do serviço da Saúde 24 Sénior, através deste design? (S/N)*

#4 Aceder ao histórico de avaliações

Tarefa 4.1 (direct task) – aceder ao histórico de avaliações
Gostaríamos de lhe pedir que aceda ao histórico de avaliações para que possa aceder à sua informação de saúde, ao longo do tempo, no programa.

Agora faça uma leitura de todo o ecrã e que descreva em voz alta o está a visualizar.

1. *Considera útil, visualizar as várias interações com o programa neste formato de cronologia (1-5)*
2. *As fotografias dos enfermeiros são uma mais valia? Ou seja, a longo prazo acha que ajudaria a gerar empatia com os comunicadores do programa durante o acompanhamento telefónico? (S/N)*

Tarefa 4.2 (direct task) – evolução da saúde
Gostaríamos de lhe pedir que aceda à outra vista deste mesmo ecrã, designada por evolução.
Aqui os conteúdos são simulados e representam a evolução da sua saúde, nas várias dimensões (Saúde, autonomia e social) e micro-dimensões (hábitos, nutrição…) avaliadas ao longo do tempo.

Aceda aos seus resultados simulados, da data X, na dimensão Social.

Quão valioso considera este tipo de informação? (1-5)

#5 Realizar uma auto-avaliação e aceder a material educativo

Tarefa 5.1 (scenario task) – realizar auto-avaliação
Imagine que o enfermeiro comunicador lhe sugeriu durante a última chamada, que realizasse uma auto-avaliação para facilitar o acompanhamento do próximo encontro, onde será feita uma reavaliação global da sua saúde.
Onde realizaria tal tarefa nesta página?

Gostaríamos de lhe pedir que a realizasse e que vá descrevendo se tem alguma dificuldade na linguagem ou na estrutura do questionário.

1. *É gratificante visualizar os seus resutados reais, sobre o seu estado de saúde integrado, de forma imediata, após a conclusão da sua auto-avaliação? (1-5)*
2. *É mais fácil responder a questões que considera mais sensíveis na auto-avaliação, através da aplicação (ex: responder por telefone ou cara-a-cara, a um prestador de cuidados)? (1-5)*

Tarefa 5.2 (direct task) – aceder ao material educativo associado

Considera ser do seu interesse, poder aceder a material educativo sobre os pontos a melhorar no seu resumo? (S/N)

Gostaríamos de lhe pedir que aceda ao "saber sobre" em algum ponto a melhorar que tenha maior curiosidade.

#6 Monitorizar os dados de saúde

Tarefa 6.1 (scenario task) – aceder à monitorização de saúde
Imagine o seguinte cenário: para que os enfermeiros da Saúde 24 possam monitorizar o estado da sua saúde entre as chamadas do acompanhamento telefónico, gostaríamos de lhe pedir que introduza algumas medicoes da sua saúde. Onde realizaria tal tarefa?

Tarefa 6.2 (direct task) – medir o peso
Gostaríamos de pedir que introduza uma nova medição do seu peso.

Tarefa 6.3 (scenario task) – monitorizar o batimento cardiaco com smartwatch
Através do relógio que tem no pulso, vamos agora medir as suas pulsações.
Pode clicar no relógio para medir a sua pulsação.

1. *Considera ser do seu interesse e cómodo, poder monitorizar parâmetros da sua saúde através de um relógio inteligente? (1-5)*
2. *Acha que a monitorização dos seus dados de saúde poderia aumentar a sua ansiedade relativamente ao seu bem estar? (1-5) – 5 é + ansiedade*

#7 Aceder ao agendamento de chamadas

Tarefa 7.1 (scenario task) – aceder ao agendamento de chamadas
Gostaríamos de lhe pedir que aceda ao menu do agendamento de chamadas.

Agora faça uma leitura de todo o ecrã e que descreva em voz alta o está a visualizar.

Considera útil ter na aplicação uma área que o ajude a gerir os contactos telefónicos do programa, tendo a possibilidade de pedir alguma alteração de data sobre um agendamento futuro? (S/N)

#8 Partilhar informação com o Portal do Utente

Tarefa 8.1 (direct task) – Partilhar informação com o Portal do Utente
Gostaríamos de lhe pedir que aceda ao menu da Partilha de Informação.

Este ecrã apresenta uma simulação do que seria a partilha de dados entre o programa de Saúde 24 Sénior e a Plataforma de Dados de Saúde, nomeadamente o Portal do Utente / Área do cidadão.

1. *Conhece a Plataforma de Dados de Saúde e o Portal do Utente / Área do cidadão? (S/N)*
2. *Já utilizou a Plataforma de Dados de Saúde e o Portal do Utente / Área do cidadão? (S/N)*

Gostaríamos de lhe pedir para ler e simular se teria interesse em autorizar ou não a partilha.

- *Autorizo a partilha com o Portal do Utente.*
- *Autorizo a partilha do resumo clinic único.*

H. Participants Consent Form

Projeto 'Saúde 24 Sénior online'

Consentimento de gravação

Muito obrigada por participar neste estudo. Iremos gravar a sua sessão por áudio, de forma a permitir que os investigadores do projeto "Saúde 24 Sénior online", do Laboratório NOVALINCS, departamento de informática da Faculdade de Ciências e Tecnologia da Universidade Nova de Lisboa possam analisar posteriormente os resultados da sua colaboração.

O teste tem uma duração prevista de 1 hora e o participante pode a qualquer momento, desistir.

Todos os dados recolhidos serão tratados de forma anonimizada no âmbito de investigação das teses de doutoramento da aluna Inês Martins Sequeira Rodolfo, e de mestrado do aluno Gonçalo Dias da Silva.

Por favor leia as condições em baixo, assinale as respectivas permissões e assine onde indicado.

Compreendo que a minha sessão será gravada via áudio. ☐

Dou permissão à Faculdade de Ciências e Tecnologia da Universidade Nova de Lisboa, para utilizar os dados recolhidos durante a sessão, apenas em contexto de investigação, incluindo as teses acimas descritas e possíveis publicações ou comunicações científicas, desde que o material seja tratado de forma anonimizada. ☐

Dou permissão para que sejam recolhidas fotos em ambiente de sessão, podendo ser futuramente utilizadas nas teses, publicações ou comunicações científicas. ☐

O nome em maiúsculas: ______________________________

Assinatura: _________________________

Data: _________________

I. Final Questionnaire

Projeto 'Saúde 24 Sénior online'

Questionário Final

Idade: ________

Género:
Feminino ___
Masculino ___

Nível de escolaridade:
Básico ___
Secundário ___
Superior ___

Frequência de uso da internet:
Pouco frequente ___
Frequente ___
Muito frequente ___

Utilização de dispositivos de tecnologia:
PC ou Mac ___
Smartphone ___
Tablet___

Utilização de serviços de saúde:
Saúde 24 geral ___
Saúde 24 Sénior___
Portal do Utente (PDS)___

Por favor dê-nos a sua opinião quanto à experiência de utilizar o produto.

A fim de avaliar o produto, por favor preencha o seguinte questionário. É constituído por pares de opostos relativos às propriedades que o produto possa ter. As graduações entre os opostos são representadas por círculos. Ao marcar um dos círculos, você pode expressar sua opinião sobre um conceito.

Exemplo:

Atraente	○	●	○	○	○	○	○	**Feio**

Esta resposta significa que avalia o produto mais **atraente** do que **feio**.

Marque a sua resposta da forma mais espontânea possível. É importante que não pense demasiado na resposta porque a sua avaliação imediata é que é importante.

Por favor, assinale sempre uma resposta, mesmo que não tenha certezas sobre um par de termos ou que os termos não se enquadrem com o produto.

Não há respostas "certas" ou respostas "erradas". A sua opinião pessoal é que conta!

Por favor, dê-nos a sua avaliação atual do produto em causa.

Por favor, marque apenas um círculo por linha.

	1	2	3	4	5	6	7	
Desagradável	○	○	○	○	○	○	○	Agradável
Incompreensível	○	○	○	○	○	○	○	Compreensível
Criativo	○	○	○	○	○	○	○	Sem criatividade
De Fácil aprendizagem	○	○	○	○	○	○	○	De difícil aprendizagem
Valioso	○	○	○	○	○	○	○	Sem valor
Aborrecido	○	○	○	○	○	○	○	Excitante
Desinteressante	○	○	○	○	○	○	○	Interessante
Imprevisível	○	○	○	○	○	○	○	Previsível
Rápido	○	○	○	○	○	○	○	Lento
Original	○	○	○	○	○	○	○	Convencional

Obstrutivo	○	○	○	○	○	○	○	Condutor
Bom	○	○	○	○	○	○	○	Mau
Complicado	○	○	○	○	○	○	○	Fácil
Desinteressante	○	○	○	○	○	○	○	Atrativo
Comum	○	○	○	○	○	○	○	Vanguardista
Incómodo	○	○	○	○	○	○	○	Cómodo
Seguro	○	○	○	○	○	○	○	Inseguro
Motivante	○	○	○	○	○	○	○	Desmotivante
Atende as expectativas	○	○	○	○	○	○	○	Não atende as expectativas
Ineficiente	○	○	○	○	○	○	○	Eficiente
Evidente	○	○	○	○	○	○	○	Confuso
Impraticável	○	○	○	○	○	○	○	Prático
Organizado	○	○	○	○	○	○	○	Desorganizado
Atraente	○	○	○	○	○	○	○	Feio
Simpático	○	○	○	○	○	○	○	Antipático
Conservador	○	○	○	○	○	○	○	Inovador

Perguntas finais

Por favor responda ainda a estas breves perguntas, marcando o valor entre 1 (discordo fortemente) a 7 (concordo fortemente) a resposta que pretende assinalar:

	Discordo fortemente						Concordo fortemente
1. Eu acho que gostaria de utilizar esta aplicação, com frequência.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
2. Eu acho que precisaria de ajuda de uma pessoa com conhecimentos técnicos para utilizar a aplicação.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
3. Eu acho que as várias funções da aplicação estão muito bem integradas.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
4. Eu imagino que a maior parte das pessoas, aprenderão a utilizar esta aplicação, rapidamente.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
5. Eu compreendo melhor a utilidade e o funcionamento do programa de Saúde 24 Sénior, através desta aplicação.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
6. Eu acho que aplicação ajuda a aumentar a minha percepção global sobre o meu estado integrado de saúde.	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7
7. Eu acho que a utilização desta aplicação poderia aumentar a minha confiança sobre a minha saúde e bem estar geral	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7

Muito obrigada pela sua participação.

J. Integrated PHR design model documentation

J.1 Functional Analysis of the Patient Portal

http://www.di.fc.ul.pt/~cad/IR/NationwidePatientPortal/Functional_Analysis_PatientPortal.pdf

J.2 Information Architecture of the Patient Portal

http://www.di.fc.ul.pt/~cad/IR/NationwidePatientPortal/Information_Architecture_PatientPortal.pdf

J.3 Mockups of the Patient Portal

http://www.di.fc.ul.pt/~cad/IR/NationwidePatientPortal/Mockups_PatientPortal.pdf

J.4 Personas of the Patient Portal

http://www.di.fc.ul.pt/~cad/IR/NationwidePatientPortal/Personas_PatientPortal.pdf

J.5 Video tutorial for the Patient Portal proposal

http://www.di.fc.ul.pt/~cad/IR/NationwidePatientPortal/PHR_DesignModel_Tutorial.mp4

J.6 Functional Analysis of the H24 Senior App

http://www.di.fc.ul.pt/~cad/IR/H24SeniorApp/Functional_Analysis_H24SeniorApp.pdf